



Parkinson Society
British Columbia

A Comprehensive Guide for Parkinson's Caregivers



You are not alone. We are here to help.

YOUR GENEROSITY makes this publication possible.

Parkinson Society British Columbia is proud to provide this booklet and other educational materials at no cost to people across the province of British Columbia and Yukon. If you find this booklet helpful, please consider a gift so that we may continue providing support services to British Columbians.

The following are ways you can support your society:

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- Special events - Your participation in our special events makes a difference
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RESOURCES

Parkinson Society British Columbia:

W: www.parkinson.bc.ca
T: 604-662-3240 | 1-800-668-3330
E: info@parkinson.bc.ca

Family Caregivers of British Columbia:

W: www.familycaregiversbc.ca
T: 250-384-0408 | 1-877-520-3267
E: info@familycaregiversbc.ca

Nidus:

W: www.nidus.ca
E: info@nidus.ca

HEALTH AUTHORITIES

Fraser Health:

W: www.fraserhealth.ca
T: 1-855-412-2121

Interior Health:

W: www.interiorhealth.ca
T: 250-469-7070

Island Health:

W: www.viha.ca
T: 1-888-533-2273

Northern Health:

W: www.northernhealth.ca
E: hello@northernhealth.ca

Providence Health:

W: www.providencehealthcare.org
T: 604-806-9090
E: communications@providencehealth.bc.ca

Vancouver Coastal Health:

W: www.vch.ca
North Shore 604-986-7111
Richmond 604-278-3361
Vancouver 604-263-7377



INTRODUCTION

Welcome to Parkinson Society British Columbia's new *Comprehensive Guide for Parkinson's Caregivers*. Parkinson's affects more than just the person with the diagnosis; it affects family and friends as well. This booklet is for those who care for people with Parkinson's disease (PD). Parkinson Society British Columbia (PSBC) recognizes the wholehearted efforts of caregivers of people with Parkinson's, and for this we are grateful.

Your journey is uniquely yours, and we are here to help. Caring for someone with Parkinson's disease can be deeply satisfying and challenging. It can draw two people closer and yet be exhausting in all aspects. You may feel a range of emotions and be unsure of how to manage them. No matter where you are on your caregiving journey, this booklet is intended to act as a guide.

Although some of the information presented here will be of interest to people with Parkinson's disease themselves, the information is intended for those who serve as primary caregivers for people with Parkinson's. The information presented here will help you prepare emotionally, physically and financially with the intention of lessening any burden, stress or conflict you may feel about your care role.

The information contained within will guide you on:

- **Parkinson's disease**
- **Living well day-to-day**
- **Developing a care plan, including planning for the future**
- **Building a care support team and communicating with healthcare professionals**
- **Support options, and**
- **Self-care**

In addition, this booklet will provide you with tips, links to helpsheets and community resources. More resources can also be found and downloaded from www.parkinson.bc.ca/resources.

The additional resources found in this booklet will provide you with practical pointers, help you reflect on your own experiences and guide you in how to access extra supports you may need.

This booklet acts as a reminder that you are not alone. PSBC is with you at every step of your Parkinson's journey. This booklet represents a labour of love and an appreciation for the commitment to care found in the Parkinson's community. This booklet may not be reproduced, in whole or in part, without the written permission of PSBC.

This booklet is only a guide. The information presented in this booklet is not meant to replace medical care or advice, but to act as a complement to the support you receive from qualified healthcare professionals.



CHAPTER 1:

A PARTNER IN PARKINSON'S CARE

LEARNING OBJECTIVES

- *What is a caregiver?*
- *Caregiver roles*
- *Caregiver types*
 - *Informal*
 - *Formal*

CAREGIVER IDENTITY

"There are only 4 kinds of people in this world. Those who have been caregivers, those who currently are caregivers, those who will be caregivers, and those who will need caregivers."

(Rosalynn Carter, First Lady of the United States, 1977-81)

"Caregiver" is the traditional term used to describe an individual who is providing support and coordinating care for another person, and/or who may be responsible for the majority of decision-making regarding the care of someone they know.

The term **"carepartner"** is also used in place of, or interchangeably with the term caregiver. Carepartner recognizes family members and friends who are playing an active role in providing support, but are not usually the sole decision maker in terms of an individual's care. Most often the term carepartner is used during the earlier stages of a disease or ailment; however, its usage in place of caregiver is also based on personal preference.

When using either of these terms, the most important consideration is how the individual providing care wishes to be addressed and recognized. This booklet will use the term "caregiver" to refer to a person providing any level and type of care to a parent, spouse, partner, adult child, another adult family member or friend; the roles and information included here are also applicable to those who consider themselves "carepartners", "carers" or otherwise.

Life with Parkinson's disease (PD) has a profound effect, not only on the person diagnosed, but also on close family members and friends. Caregiving can be both rewarding and challenging. Care is not limited to the physical tasks, but can also include emotional and spiritual support. Each person's journey is unlike.

Just as the person with Parkinson's disease has a unique outlook, so does the caregiver. Some caregivers are overprotective; some deny and ignore or explain away the symptoms; while others are proactive. It is important to assess your individual strengths, as this will shape your role as a caregiver.

Supplement your strengths with support from others; this will allow you to enhance your abilities in areas that you feel less confident. Taking a proactive approach means you can participate in making informed decisions and be involved in healthcare discussions. It will also allow you to implement the support you will need for yourself and the person you are caring for.

FAMILY CAREGIVING

"The hardest part for any caregiver, whether it is a child, parent or spouse, is the relationship change. Changes occur over time with the illness. Physically, [patients] are not as mobile; they are not able to do things with you like they used to. The medications might affect their cognitive ability. They may not be able to speak as well.... That is where you [transition] from a wife or a husband to a carepartner or caregiver."

(Lonnie Ali, wife to Muhammad Ali, American Association of Retired Persons, June 2014)

The relationship between the person with Parkinson's and the caregiver(s) is truly a care partnership. **A PD diagnosis creates the need for families to negotiate new roles, responsibilities, and coping methods.** Since Parkinson's is a progressive disease, there is a need to continually adapt to the changing demands. While caring for a loved one can bring families closer together and enhance relationships, it can also distance families and diminish relationships.

Family caregivers provide different types of care based on their relationship with the person with PD. Spouses tend to be care providers (i.e., perform the majority of the care tasks), while adult children and other relatives tend to be care managers (i.e., organize the healthcare team and make decisions around care needs). However, every situation is different and many caregivers perform a combination of these tasks.

SPOUSES AS CAREGIVERS

The long-term commitment and closeness of relationships may contribute to viewing caregiving as a normal next step. However, caring for a spouse with Parkinson's can be difficult. In fact, care providers tend to be more stressed than care managers since the social expectations associated with being a spouse may add emotional burden.

Caregiver strain can start for spouses early in the disease and become more intensive as Parkinson's progresses. However, some may find that in later stages, spouses are armed with more tools (i.e., coping strategies), support (i.e., support group, emotional support from family/friends) and resources (i.e., home care, respite, education) to help manage the increased care demands.

A diagnosis of Parkinson's can shift the dynamic in a couple's relationship, requiring adjustments as the disease progresses. Caring for a spouse may also strengthen the spousal relationship through improved communication and a shared sense of self-confidence in meeting the demands of a progressive disease.

Communication and reciprocal understanding are important tools to overcome changing care dynamics.

(Carter et al., 1998; Raschick & Ingersoll-Dayton, 2004)

ADULT CHILDREN AS CAREGIVERS

A growing segment of the Canadian population includes adult children providing care to a parent. Parents may move into adult children's households, where the adult child may manage multiple roles, such as working and caring for their own children. This is known as the "sandwich generation". Adult children may also move closer to their parents, the parent may relocate to be near the adult child, or care may be provided from a distance.

Adult children as caregivers may provide care associated with emotional, physical, financial, household, decision-making, and social support. Geographic distance, income, gender, work, and their own family responsibilities can influence the type of support adult children are able to provide.

Chronic illness creates shifts in independence and dependence within a parent-child relationship. Some parent-child relationships adjust to a diagnosis of Parkinson's disease with ease, while others experience a disconnection, lack of understanding and/or poor communication. **There may be a greater likelihood for role reversals to occur between a parent and adult child when a parent is diagnosed with Parkinson's disease, leaving the adult child with more of a decision-making role and/or care manager role.** Role-reversal can be difficult to adapt to, especially if the adult child looked up to their parent and now sees them as vulnerable.

Providing care for a parent with Parkinson's may improve interpersonal skills, patience, personal growth, compassion, meaning, and a sense of commitment that reflects the quality of the relationship with a parent.

(Blanchard, Hodgson, Lamson, & Dosser, 2009; Brodaty & Donkin, 2009; Habermann & Davis, 2005; Habermann, Hines, & Davis, 2013; Raschick & Ingersoll-Dayton, 2004)

PROFESSIONAL CAREGIVING

Not everyone wants to be a full-time caregiver – and that's okay! Sometimes it is too difficult to cope with the care duties required. There also may come a time when you need to hire help – be proactive so you are prepared when that time comes. See CHAPTER 4 for more details on home, community and residential care options in British Columbia, as well as for considerations on preparing professional caregivers.

Some considerations when hiring professional caregiving services:

Skill Requirements

What are the person with Parkinson's specific care needs?

- Companionship
- Hygiene (e.g., bathing, dressing, toileting)
- Physical assistance (e.g., walking)
- Homemaking (e.g., finances, meal preparation, laundry, transportation, shopping)
- Special disease care (e.g., dementia)
- Medication (e.g., timing, blood pressure, diabetes)

What type of healthcare or other training is needed to complete the tasks listed above (e.g., lifting care recipient, transportation, or skills related to disability and/or cognitive impairment)?

What are you and your care recipient's values/preferences (e.g., language, male/female)?

Administrative Issues

- Will the same caregiver come for every shift? If not, how many will be alternating and what is the schedule?
- What happens if the hired caregiver becomes ill or is otherwise unavailable? What are the alternate arrangements?
- Who is responsible for payments related to professional caregiving?
- Will you or the person with Parkinson's deduct and pay personal income tax contributions from the hired caregiver's pay?
- What are the Canada Pension Plan and Employment Insurance contributions related to hiring a caregiver?

- If the caregiver is injured at a client's residence, who is responsible? Many homeowners' insurance policies exclude injuries to hired caregivers.
- Does the hiring organization perform criminal background checks?
- Do they check references from prior work history?
- Can they verify the caregiver is legally able to work in Canada?
- How is it documented that services were complete?
- Who is responsible for determining the job contract including wages, vacations, payment method and schedule, hours, duties, and termination guidelines?

LIVE-IN CAREGIVERS OR CARE AIDS

Families can hire a foreign caregiver to provide care in a private residence to persons with certified medical needs. Caregivers must provide full-time care (minimum 30 hours per week), work in a private household, and meet the requirements set by Employment and Social Development Canada (ESDC)/Service Immigration, Refugees and Citizenship Canada (IRCC).

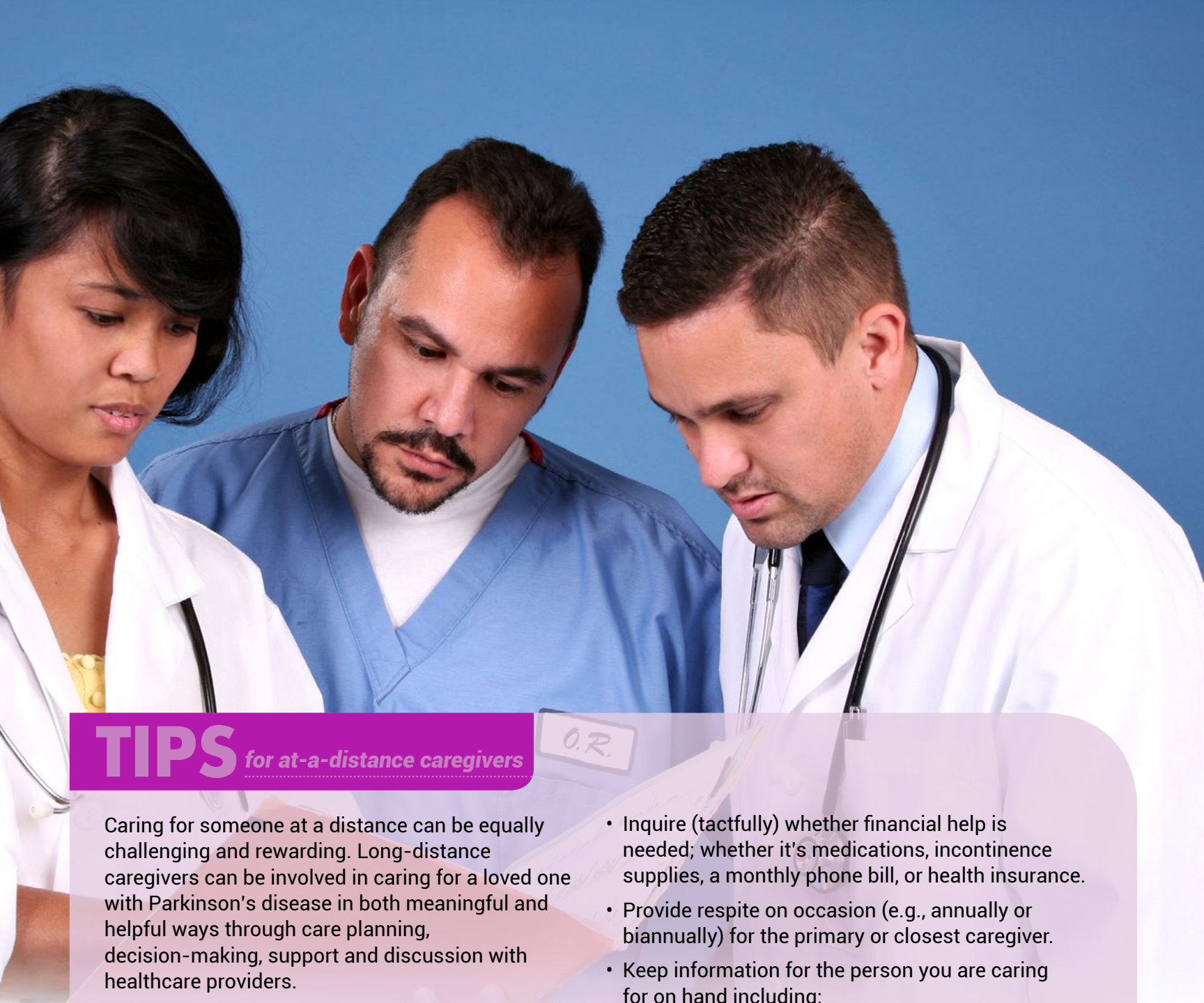
Categories of workers include:

- Registered nurse
- Licensed practical nurse
- Attendant for persons with disabilities, home-support worker, live-in caregiver, personal care attendant

Further information on eligibility and the application process can be found on the Government of Canada's website for Immigration, Refugees, and Citizenship Canada (IRCC) at www.cic.gc.ca/English/work/caregiver/index.asp.

The Government of Canada's IRCC call center (1-888-242-2100) is available to answer your questions Monday to Friday 8am to 4pm.

(Green, n.d.; Family Caregiver Alliance, 2016)



TIPS *for at-a-distance caregivers*

Caring for someone at a distance can be equally challenging and rewarding. Long-distance caregivers can be involved in caring for a loved one with Parkinson's disease in both meaningful and helpful ways through care planning, decision-making, support and discussion with healthcare providers.

- Learn about Parkinson's disease progression, medication, and other therapies so you can help with decision-making and care planning.
- Offer perspective, guidance and support to the person with Parkinson's disease and their primary caregiver or closest caregiver.
- Offer to be in contact with any healthcare professionals around care needs via telephone/email, establishing expectations around disclosure and patient privacy with everyone involved.
- Establish a regular routine to contact the person with Parkinson's disease through phone calls, email, letters, photos, video calling, etc.
- Inquire (tactfully) whether financial help is needed; whether it's medications, incontinence supplies, a monthly phone bill, or health insurance.
- Provide respite on occasion (e.g., annually or biannually) for the primary or closest caregiver.
- Keep information for the person you are caring for on hand including:
 - Date of birth
 - SIN number
 - Healthcare number
 - Insurance information
 - List of medication
 - Names and locations of healthcare providers
 - Copies of Advanced Directives, Representation Agreement and Enduring Power of Attorney.

(Family Caregivers of British Columbia, 2017)

For more information on this topic, see the Caregiving and Family resource section of Parkinson Society British Columbia's website at www.parkinson.bc.ca/resources-services/resources/#caregiving.



CHAPTER 2: MAINTAINING DAILY LIVING

LEARNING OBJECTIVES

- *The importance of well-being*
 - *Work-life balance*
- *Care Plans*
 - *At home*
 - *In the hospital*
- *Activities of daily living*

THE IMPORTANCE OF WELL- BEING

Health is the balance of positive and negative variables. Negative variables (like burden or stress) predict strain for caregivers, while positive variables provide a buffer for the strain and improve well-being. Important positive buffers include:

Preparedness: how prepared you feel for the role and how quickly you adjust to the role. Being prepared is about choosing to assume the role and beginning to make realistic plans.

Good relationship quality: good relationship quality with your care recipient has been found to lower levels of depressive symptoms and improve physical health in caregivers. Honest and open communication is the foundation for a good relationship, as well as mutual acceptance, enjoying each other's company and making a commitment to be there for each other.

Meaningful experience: the ability to draw meaning from the care experience as positive. Use this role as a way to learn something new about yourself or find strength in your ability to comfort and care for your loved one.



WORK-LIFE BALANCE

Work-life balance is when an individual attempts to balance responsibilities with time for oneself. It means having enough time for self-care or to decompress.

Achieving work-life balance can be difficult, especially in the role of a caregiver. The caregiving role is a time commitment and it can be daunting to balance your life while taking on these caregiving duties.

The caregiving role may not only interfere with your self-care activities, but also your employment, other commitments outside the home, and/or relationships with family and friends. To fulfill your caregiving obligations, you may need to take time off or decrease your responsibilities. When employers are not supportive of your needs, decreased job satisfaction, financial strain and fatigue may ensue.

TALKING WITH YOUR FAMILY AND FRIENDS ABOUT PARKINSON'S

Parkinson's disease often hides from the public, and can be confusing and unpredictable. Medication may mask symptoms and those who are not close to you may find it difficult to understand the care commitment that is required. Communication is key to understanding.

When you and the person you are caring for decide to break the news of a Parkinson's diagnosis to family, friends and others, it can be stressful. Take the time to prepare, decide how much information to disclose, and time your delivery in an appropriate situation when nothing else is scheduled. Invite others to talk about their feelings and concerns.

As a caregiver, find someone you can trust to talk openly and honestly about your experiences and needs. Support groups can be a powerful way to connect with other caregivers, obtain support, further knowledge of the disease and share experiences.

Find a PSBC Support Group near you by visiting the website at www.parkinson.bc.ca/supportgroups.

TIPS for working carepartners

- Speak to your supervisor or Human Resources department to create an action plan. Be specific about your needs and what work tasks you are accountable for.
- Research the programs, policies and benefits available to you at your workplace.
- Be proactive. Speak with coworkers about your situation so they know what you are going through, and discuss the possibility of sharing some workload when necessary.
- Discuss telecommuting, work-from-home opportunities, flex-time or job-sharing options.
- Make time for activities that you enjoy and increase your energy. Even if you don't feel like it. Remember – getting started is the hardest part.
- Plan a family meeting to:
 - (a) discuss alternative care options when you may not be able to provide care and
 - (b) avoid duplication of care efforts.
- Plan for emergencies.
- Ensure your own medical and health needs are met.
- Seek out resources to help you navigate the system; for example, explore respite options.
- Find a support group or supportive friends to share your challenges and successes.

(Canadian Mental Health Association, 2017)

The Canadian Mental Health Association can be contacted by phoning 1-613-745-7750, emailing info@cmha.ca or on their website www.cmha.ca.

DEVELOPING A CARE PLAN

Parkinson's disease is a slowly progressive disease, and care needs gradually increase over time. The subtle nature of symptom progression allows everyone to gradually adjust to the increased care needs, but it can also be frustrating to predict what symptoms may be more troublesome in the future. Having a care plan (and preparing for the future) frees up energy to enjoy the good times still to come in your loved one's life.

Here are some questions to consider when discussing what level of care arrangements are required with your loved one.

AT HOME

- What level of care is currently needed for the person with Parkinson's daily activities, such as bathing, dressing, shopping, eating, mood, mobility, toileting, etc.?
- What are his/her medication considerations?
- Is home care a viable option in your household? Is your house large enough to accommodate mobility aids, bedside aids or other medical equipment? Is the home environment safe (i.e., physical layout, stairs) or are structural changes needed (i.e., handrails, ramps)?
- Are arrangements needed for transportation, medication and housekeeping? At what point will this type of assistance be needed?
- Are these financially feasible and/or what financial supports are available?

Case managers, as well as community physiotherapists and occupational therapists, may be helpful to provide expertise on the person with Parkinson's current needs, safety concerns and possible considerations in the future. They can provide you with options during a home assessment plan, and consider both public and private funding options.

You can contact Home and Community Care through your local health authority to have a community therapist perform a home safety assessment. Local Health Authority contact information is listed in CHAPTER 4.

IN THE HOSPITAL

A care plan is important when your loved one is admitted to hospital for either a routine reason or emergency. While routine hospital admittance means you have time to plan, an emergency necessitates being prepared and having a care plan already in order. A nurse will also work with you and your loved one through care planning for when they are discharged.

Consider recording the details of your care plan in a notebook with contact information for all healthcare professionals involved. Note what works for you and the person in your care, and make any changes necessary. Understand that, in a hospital setting, your loved one becomes subject to the care and protocols within the hospital. At the outset it is helpful to make contact with the staff administrator in the hospital who will be responsible for coordinating your loved one's hospital stay, including discharge. Do not hesitate to contact this person if you see any aspects of your loved one's care going awry (e.g., medication mismanagement).

Be prepared for hospital visits with your very own Aware in Care Kits from PSBC: www.parkinson.bc.ca/awareincare.

People with Parkinson's **MUST NOT** take certain medications:

Please contact Parkinson Society British Columbia for an Aware in Care kit by calling 604-662-3240, 1-800-668-3330, by e-mailing info@parkinson.bc.ca or visiting www.parkinson.bc.ca/awareincare.

- All neuroleptics, except atypicals
- All conventional antipsychotics
(e.g., haloperidol, risperidone, olanzapine)
- Major tranquilizers
- Certain drugs for nausea
(e.g., prochlorperazine and metoclopramide)
- Demerol – use with caution



TIPS for the hospital

- Ask questions about why something is/is not being done.
- Be prepared to answer questions about treatment decisions for your loved in case of emergency (e.g., “do not resuscitate” instructions or guidelines around blood transfusions).
- Only agree to procedures that make sense to the values and circumstances of the person in your care. In the case of disagreements, request a family meeting or inquire what other support services may be available (e.g., spiritual care provider, elder, translator, ethics committee). If there are persistent disagreements, seek out a second opinion and inquire as to the dispute resolution process.
- Assist with grooming and care.
- Be friendly and respectful to staff.
- Be prepared to receive little notice of discharge.
- Use PSBC's Aware in Care Kit to inform facility staff of the importance of Parkinson's medication timing. The timing of Parkinson's medication is extremely important and the facility staff may not understand the need to strictly follow your prescribed medication schedule.
- Remind hospital staff that dopamine-replacement medication may have adverse reactions with other medications routinely used in a hospital setting (e.g., sedation medication, Ativan).

TIPS *for hospital discharge*

UPON DISCHARGE FROM THE HOSPITAL

- Speak up if you doubt the time is right – meet with the hospital's discharge planner (e.g., social worker or hospitalist) to voice your concerns.
- Ensure you and your loved one understand the diagnosis (identification of the nature of an illness or symptoms) and prognosis (likely course of the disease) before going home.
- Get written care instructions, including prescriptions, which should also be shared with your family physician.
- Fill prescriptions provided by the hospital before you get home.
- Arrange hospital-based follow-up care where available and required.
- Understand what home care benefits the person with Parkinson's is eligible for and able to receive – speak with the social worker or hospitalist.
- Arrange for home care and/or other therapies where needed.
- Take all personal items home with you.
- Arrange transportation home.

For more information on this topic, see Parkinson Society British Columbia's Aware in Care Kit resource at www.parkinson.bc.ca/awareincare.



INDEPENDENCE AND ACTIVITIES OF DAILY LIVING

"I prefer to call this relationship a "care partnership" because I believe it is one that is truly reciprocal. As a person with Parkinson's disease adjusts to physical changes and, at times, to changes in personal independence, the carepartner must learn to adapt to a different relationship dynamic and perhaps to greater "ownership" of duties that their partner had previously handled (e.g., finances or household management)."

(Rhona Johnson, Parkinson Disease Foundation Newsletter, Spring 2008)

Activities of daily living (ADL) include bathing, grooming, dressing, preparing and eating food, caring for the home, timing/management of medication, communication, mobility and sitting, standing, walking, exercise and recreational activities. **To preserve independence in ADL, the person with Parkinson's disease should be encouraged to do all the tasks he/she can for himself/herself.** It is important to note that the person with Parkinson's ability to do tasks vary throughout the day because of response to medication and fluctuations in function.

Depending on the level of impairment, ADL may become more challenging. Medical treatment can help control symptoms and improve function, but it also requires careful management during day-to-day living to minimize other side effects. When asked, you can offer specific strategies and tools to assist the person with Parkinson's disease in staying as independent as possible. These can include assistive devices, changes in the home and movement strategies. When ADL become too challenging for you and/or the person with Parkinson's disease to manage on your own, there are professionals who can help.

WHO CAN HELP WITH ACTIVITIES OF DAILY LIVING?

- **Nurse or nurse practitioner** can offer advice related to symptom and medication management.
- **Physiotherapist** can offer help by teaching mobility strategies (i.e., specific exercise plan, transfers, auditory/visual cues), home modifications and mobility aids. Visit www.cptbc.org for more information.
- **Occupational therapist** can recommend modifications to your home, advice on dressing, toileting, grooming, technological adaptations, leisure and recreation modifications, and adaptive equipment. Visit www.cotbc.org for more information.
- **Speech-language pathologist** can provide adaptive techniques for communication, voice and swallowing difficulties. Visit www.cshhpb.org and/or www.lsvtglobal.com for more information.
- **Dietitian** can recommend feeding and eating techniques, as well as diet modifications to address common Parkinson's disease symptoms (i.e., constipation). Dial-A-Dietitian is a free nutritional hotline that can be reached at **604-732-9191** or **toll-free at 1-800-667-3438**. Visit www.collegeofdietitiansofbc.org for more information.
- **Pharmacists** can provide valuable information about medications interaction, dosing and alternatives. They may ask about swallowing difficulties and offer alternatives when patients begin to have challenges with oral medications. Visit www.bcpharmacists.org for more information.

For more information on this topic, see PSBC's helpsheet, *Your Healthcare Team and How to Access it*, at www.parkinson.bc.ca/resources.

CONSIDERATIONS FOR ACTIVITIES OF DAILY LIVING

In general

- Work with a physical and/or occupational therapist
- Encourage regular movement as part of a daily routine
- Let the person with Parkinson's help with tasks that he/she can still do and give no more assistance than is needed
- Consider buying adaptive equipment
- See PSBC's *Assistive Devices, Home Adaptations and Funding* helpsheet

Home environment

- Ensure enough space between furniture for mobility limitations and/or mobility aids
- Remove tripping hazards (e.g., cords, wires, low tables)
- Secure rugs or remove them, and consider using thin pile carpets
- Place non-skid tape on the edges of steps
- Provide extra railings along stairways for support
- Use leveler-style handles on doors
- Ensure rooms are well-lit and use automatic night lights
- Have a telephone with large buttons, handsets with amplifiers, step-by-step instructions and list of important phone numbers
- See PSBC's *In-Home Safety Check* helpsheet

Toileting

- Create a regular toileting schedule to deal with bladder changes caused by Parkinson's disease
- Limit water intake in the evenings
- Use an elevated toilet or seat
- Use stool softener (e.g., Miralax)
- Consider incontinence pads
- Ensure proper cleaning using biodegradable hygiene wipes and hand washing
- See PSBC's *Bathroom Safety* helpsheet

Bathing

- Prepare all needed supplies beforehand and adjust water temperature and pressure
- Consider a walk-in shower with a handheld nozzle, grab bars, a tub bench or a bed bath
- Use non-slip bath mats
- Have the person with Parkinson's get out of the tub before draining it, as a full tub will help keep them buoyant

- Have the person sit on a towel on the toilet seat or a chair to dry off; consider using a blow-dryer to dry off
- If needed, rest after bathing

Oral care

- Create a regular oral care schedule
- Medication can cause dry mouth and decreased saliva, making the person with Parkinson's disease more susceptible to tooth, gum and bone decay
- Consider using an electric toothbrush, if recommended by dentist
- Use floss holders to make flossing easier
- See PSBC's *Dental Care* helpsheet

Dressing

- Ensure plenty of time for the dressing routine
- Choose loose comfortable clothing with elastic, Velcro and front fasteners
- If needed, dress the person while he/she is sitting
- Simplify your dressing area and storage so clothing is easy to reach
- Dress the more affected side first
- See PSBC's *Dressing* helpsheet

Eating and diet

- Allow enough time for eating
- Provide a comfortable upright seating arrangement
- Prepare all items beforehand and ensure they are within reach
- Ensure food is well chewed and swallowed properly
- Ensure the person takes small sips of liquid between each bite
- Use straws, if needed
- Offer smaller, frequent meals or a nourishing snack between meals
- Allow the person to eat with his/her fingers if that is easier
- Remind the person to keep his/her chin down when swallowing
- Remove distractions
- Use adaptive utensils and cups
- Be aware of a dry or never dry mouth as a side effect of medication or swallowing difficulties, respectively

- Take medication 1 hour before eating to ensure proper absorption
- Avoid high-protein foods when taking levodopa medication to ensure it is absorbed properly
- Ensure person is getting enough fibre and plenty of water to avoid constipation
- Boost calorie intake (dairy, nuts, seeds, honey) if weight loss is an issue
- See PSBC's *Nutrition* helpsheet

Sit-to-stand

- Have the person get their hips to the edge of the chair
- Plant feet firmly underneath hips
- Have the person place both hands on armrest or stable equipment in front of them
- Use cue "nose over toes" to get the person to lean forward while pressing their hands into the seat and lifting out of the chair
- See PSBC's *Stay on Your Feet* booklet and *Balance and Falling* helpsheet

Walking

- Avoid distractions
- Have the person with Parkinson's focus on taking large steps with the cue "big steps"
- To avoid festination (a toe-first step causing accelerating) cue the person to "lift your knees"
- See PSBC's *Walking and Stiffness and Slowness* helpsheets

Freezing

- Have the person make wider turns
- Count, clap or use a rhythmic auditory cue and get the person to step to the beat
- Use a visual cue (e.g., laser pointer, cane, foot or sidewalk lines) and get the person to step over it
- See PSBC's *Freezing* helpsheet

Medication

- You (or a pharmacist) can package a weekly pillbox (or pill pack) with a secure lid to organize all medication
- Consider a pillbox with removable compartments so you can take just what you need on daily outings
- Consider using one pillbox per day if your loved one has more than four daily doses
- Set reminder for pills with a timer (i.e. kitchen timer, cell phone, watch) and ensure medication is

taken right away when timer goes off

- Check with your physician/pharmacist before your loved one takes any over-the-counter medication to avoid potential interaction with Parkinson's medications
- Continue medication as prescribed unless otherwise directed. Speak with your physician/pharmacist before making any changes, including stopping medication, altering dose schedule, crushing or splitting pills, etc.
- See PSBC's resources on *Treatment* (Meyer, Derr, & Imke, 2007)

Equipment/aids for activities of daily living

Don't feel guilty for not doing things for your loved one that they can be doing for themselves. Instead, look for ways to help them do what they are able to do. Something as simple as a pill dispenser can help the person with Parkinson's disease become more independent - and can free up precious time for you. Here are some equipment/aids to consider using:

- Grab bars in tub, shower, beside toilet and on edge of vanity
- Use a "reacher" device to get objects in high and low places without stretching or bending over
- Raised toilet seat
- Wheelchair
- Walker
- Electric scooter
- Cane
- Gait/transfer belt
- Sight and hearing aids
- Swivel spoons
- Utensil grips
- Plate guards
- Two handled mug
- Spill proof cups
- Button hooks
- Shoe horn
- Elastic shoelaces
- Pill timers with multiple alarms
- Walking poles

You can also contact a Home and Community Care office through your local health authority to have a Case Manager perform a home safety assessment. **Local health authority contact information is listed in CHAPTER 4.**



CHAPTER 3:

PAYING ATTENTION TO PD ASSOCIATED CHANGES

LEARNING OBJECTIVES

- *Motor symptoms*
- *Non-motor symptoms*

Parkinson's disease is the second most common neuro-degenerative disorder after Alzheimer's disease and affects both motor and non-motor functioning.

Parkinson's disease (PD) is a progressive neurological disorder resulting from the loss of dopamine in a part of the brain called the substantia nigra. Dopamine acts as a chemical messenger, allowing nerve impulses to travel smoothly from one nerve cell to another. This enables the transmission of messages to muscles of the body to begin voluntary movement. As dopamine continues to decrease, muscle movements become slower and more rigid, tremors can develop and reflexes become more impaired contributing to a loss of balance. Dopamine is also essential for the control of blood pressure and bowel function, and can affect mood and thinking. The symptoms of PD appear when over half of the dopamine cells are lost. The progression of the disease and accompanying symptoms vary with each individual.

At present there is no cure, however, the symptoms of PD can be treated with medication. In some cases, surgery can be effective. The drugs used to treat PD either replace the lost dopamine or mimic the action of dopamine in the brain. Increasing the amount of dopamine can alleviate the symptoms, but does not slow disease progression. As the symptoms worsen, more medication is needed. **Find out more about Parkinson's medication by reading PSBC's Medication helpsheet.**

WHAT ARE MOTOR CHANGES IN PEOPLE WITH PARKINSON'S?

Parkinson's disease (PD) manifests itself through a wide spectrum of symptoms. While there are many potential challenges, keep in mind that the disease is unique to every individual. The more common motor changes that people with Parkinson's experience can be remembered and understood using the mnemonic **T.R.A.P.**

TREMOR

Consists of a repetitive shaking movement that usually appears when a person's muscles are relaxed. Tremors are unilateral and disappear with action or sleep. Often occurs in the hands, arms or legs, and is the first symptom to appear in 70% of persons with Parkinson's disease.

RIGIDITY

Refers to increased resistance or stiffness in muscles, which makes movement difficult. Rigidity, which may be associated with pain, can occur in the neck, shoulders, hips, wrists, ankles, etc.

AKINESIA (OR BRADYKINESIA)

Refers to slowness of movements and is the most characteristic clinical feature of Parkinson's disease. Initially it manifests as slowness in performing activities of daily living (e.g., walking), difficulty with fine motor control (e.g., writing), slow movement and reaction time. It can encompass difficulties in planning sequential and simultaneous tasks, loss of spontaneous movements, drooling, loss of facial expression, and reduced arm swing while walking. It can also include internal processes, such as movement of food through the gut, which may cause constipation.

POSTURAL INSTABILITY

Consists of difficulties in maintaining balance, standing up straight and/or walking. This loss of postural reflexes and change in balance typically occurs in the later stages of Parkinson's disease. It is the most common cause of falls and risk for hip fractures.

OTHER GAIT DISTURBANCES

A change in walking pattern that can increase your risk of falling, such as festination, a toe-first step causing accelerating, rapid and short steps.

Freezing

This is the sudden inability to take a step that can occur when turning corners, moving through a narrow space, rising from a chair and/or being distracted. Freezing is associated with "wearing off" of medication and "on/off" episodes.

WHAT ARE NON-MOTOR CHANGES IN PEOPLE WITH PARKINSON'S?

While tremor, gait and balance may take centre stage, the effects of Parkinson's disease on mood, memory and sleep in people with Parkinson's are often not discussed. In some circumstances, non-motor changes pose greater challenges for the person with Parkinson's and their caregiver. Changes can cause dependence in daily life for the person with PD and distress for the caregiver. With advanced age and longer disease duration, changes in cognition, mood and sleep may become evident and progressively worse.

COGNITIVE CHANGES

Cognition

The set of all mental abilities and processes related to discovering and understanding the world around us, and how we apply knowledge from day-to-day. It includes: attention, perception, memory, emotion, imagination, reason, beliefs, intelligence, judgment, evaluation, reasoning, problem solving, decision-making and communication.

Dementia

A broad category of brain diseases that cause a long-term and serious decline in the way a person is able to think and remember. It is the decline in cognitive abilities that are severe enough where they have a significant impact on daily functioning. Dementia is an umbrella term that includes a range of symptomology and diseases such as Alzheimer's disease, vascular dementia, fronto-temporal dementia, dementia with Lewy Bodies, and Parkinson's disease dementia.

Parkinson's disease dementia

A diagnosis of dementia in Parkinson's disease represents progression of the disease, usually after quite a number of years of motor impairment. Diagnosis of dementia in Parkinson's is made at least one year after the onset of motor symptoms. Dementia is slowly progressing cognitive impairments that compromise independent functioning. Clinical features that indicate Parkinson's disease dementia can vary from other dementias, like Alzheimer's disease, and include: fluctuating attention, poor visuospatial function, impaired short-term memory, apathy, depression, hallucinations and/or delusions.

It should be noted that people with PD who have recently developed cognitive problems should be evaluated by their physician or neurologist to make sure other factors (i.e., side effects of medication, stroke, thyroid, nutritional deficiencies) are not causing these symptoms.

Memory

In Parkinson's disease, there is impairment in the recall portion of memory; this is different from difficulty encoding (or getting the information), as seen in Alzheimer's disease. The delay in accessing the right information (recall) may be related to changes in executive function associated with Parkinson's disease, or bradyphrenia, which is slowed thinking resulting in the need for longer time and more effort to complete mental tasks.

Symptoms of cognitive decline/dementia in Parkinson's disease:

- Forgetfulness
- Fluctuating attention
- Difficulty concentrating
- Difficulty with information retrieval
- Slow thought process
- Altered judgment and changes in perception
- Visuospatial difficulties
- Difficulty with word-finding, articulation
- Difficulty making decisions
- Difficulty with planning and sequencing
- Difficulty with problem solving
- Hallucinations
- Behaviour changes (i.e. aggression)
- Depression
- Anxiety
- Apathy
- Sleep disturbances



Executive Function

Executive function is like the conductor of the brain's orchestra; it is a set of processes that have to deal with managing oneself and resources in order to achieve a goal (i.e., complete a task). In Parkinson's disease, people often demonstrate an inability to plan and sequence information, probably due to slowness and difficulty in memory retrieval strategies (recall). Changes in executive function may result in difficulty with controlling thoughts, goal-directed behaviours and adopting new strategies. These changes in information processing can present challenges for an individual to self-monitor, problem-solve and multi-task.

Attention

Cognitive changes in Parkinson's disease may make it difficult for people with Parkinson's to pay attention—particularly, if required to selectively focus on one aspect of the environment and ignore competing stimuli. Fluctuations in attention may show up as drowsiness, staring into space, long naps or disorganized speech. Finally, it may be challenging for a person with Parkinson's to respond to multi-tasking; for example, driving while reading a billboard or walking and talking at the same time. This can have implications for safety, such as falls.

Visuospatial

People with Parkinson's may have difficulty perceiving, processing and acting on visual information. This can make it difficult to navigate routes, estimate distances or form a mental image of where things are in space (i.e., mental mapping). The inability to judge distances increases the risk for falls (i.e., tripping on a curb). Furthermore, if the person with Parkinson's cannot adequately consider spatial contextual information, this may lead to trouble remembering locations of objects or places.

Hallucinations

Hallucinations are when a person sees or hears something that is not there. In Parkinson's disease, the most common hallucinations are visual, while less than 10% of people have auditory hallucinations. Hallucinations tend to be complex story lines with Lilliputian animals or people (i.e., small people, animals, things and/or children). If hallucinations come on suddenly, see a physician or neurologist to rule out urinary tract infection, pneumonia or medication side effects. When hallucinations are non-threatening, and the person with Parkinson's still has insight, it is sometimes best to "go along with it" and continue the current care regime.

If the person with Parkinson's is experiencing threatening, paranoid or aggressive hallucinations, see a physician or neurologist.

Considerations for helping a person with Parkinson's with declining cognitive health

- Establish a regular schedule
- Have a daily schedule posted in the same place
- Mark days on a calendar; colour code your and the person with Parkinson's' appointments and activities
- Put reminders in a prominent, consistent place and use visual, verbal and auditory reminders
- Write to-do action lists and include photos, time lines and/or detailed step-by-step instructions
- Place lists and/or instructions by the task-at-hand or item (e.g., television, microwave)
- Reduce clutter and distractions (i.e., visual and auditory) to make it easier for someone to focus
- Keep items in the same place
- Label drawers/cabinets
- Have spaces in your house where certain activities are done (e.g., reading nook, eating only at the kitchen table, office desk only for finances and household management)
- Get sufficient physical exercise
- Incorporate brain games or mental exercises into your routine, including counting, math, crosswords, puzzles, card games, reading and learning a new activity or skill
- Incorporate social interactions, as they are an important piece of mental stimulation
- Medication is available to manage cognitive changes in Parkinson's disease (e.g., Exelon, Aricept or Razadyne); however, long-term data of its effectiveness is inconclusive. Talk to a physician or neurologist about these medications
- Antipsychotics, such as Seroquel or Clozaril, may be used in persons with Parkinson's with a low risk of aggravating motor symptoms
- Read PSBC's resources on mental and cognitive health

COMMUNICATION CHALLENGES

Language deficits in Parkinson's disease can include word recall, word finding (i.e., naming items) and difficulty in following long, complex sentences. Ninety percent of people with Parkinson's experience changes to their voice; it may become quieter, breathier, hoarse, less precise and difficult to understand. People with Parkinson's may have difficulty coming up with the right word because of bradyphrenia (slowed thinking) and delayed memory recall.

Considerations for communication

- Have a conversation one-on-one, with eye contact
- Reduce distractions
- Speak slowly and carefully, and pay attention to non-verbal communications
- Repeat important information
- Communicate during "On" periods and avoid periods of sleepiness or anxiety
- Encourage the person with Parkinson's to think loud before speaking to enhance voice volume
- Remember, masked facial expression may inhibit the person with Parkinson's from expressing themselves physically
- Be patient. Give the person with Parkinson's time to respond or participate
- Ask if you can provide a cue to assist them in finding the right word
- Ask one question at a time
- Consider asking close-ended questions: give the person with Parkinson's options ("do you want soup or a sandwich?") or yes/no questions ("do you want coffee?"), rather than open-ended questions ("what do you want?")
- Use gestures when talking with the person with Parkinson's
- Have hearing and vision tested
- Find a Speech Language Pathologist trained in Lee Silverman Voice Treatment® (LSVT®) to increase vocal volume, pace and facial expressions
- Read PSBC's helpsheet on enhancing communication with a person with Parkinson's

(Aarsland et al., 2007; Docherty & Burn, 2010; Dubois et al., 2007; Emre et al., 2007; Emre, Ford, Bilgiç, & Uç, 2014; Litvan et al., 2012; Pagano et al., 2015; Stoessl, 2013)

Visit the LSVT® website www.lsvtglobal.com to find a clinician, **call toll-free 1-888-438-5788** or **e-mail info@lsvtglobal.com**.



MOOD CHANGES

Parkinson's disease is considered a movement disorder; however at least 50% of people with Parkinson's disease experience depression and/or anxiety. These changes in mood can be caused by a reaction to a diagnosis, symptoms and concerns about the future. In addition, mood changes can occur because Parkinson's disease affects the brain pathways closely associated with mood and sleep. Changes in mood may also be a side effect of the medication used to manage Parkinson's symptoms.

Moods, internal emotional states, can affect an individual's judgment and perception. For instance, negative moods can include: depression, anxiety, aggression, distress, poor self-esteem, apathy and fatigue.

In Parkinson's disease, depression and anxiety can contribute to the worsening of motor symptoms, gait difficulties, freezing, on-off fluctuations, cognitive decline and quality of life. As a caregiver, this makes it an important non-motor symptom to pay attention to.

Do not dismiss signs of depression in the person with Parkinson's because you may assume it is normal when he/she is faced with such illness. Depression and anxiety are treatable, but it is important to not let them go unnoticed and untreated. As a caregiver, encourage your loved one to bring up with their healthcare professional feelings of depression or anxiety, or difficulties doing the things they would normally enjoy.

To become more informed about mood changes in Parkinson's, read PSBC's helpsheets about apathy, depression, anxiety and mood disturbances.

Considerations for managing mood changes in the person with Parkinson's

- Learn to identify and name the experienced emotion
- Schedule fewer activities per day but continue to stay involved in meaningful social and recreational activities
- Consider separating activities/tasks into shorter periods with breaks in-between
- Ensure adequate sleep. More assistance may be needed when the person with Parkinson's disease is feeling fatigued
- Avoid tasks that require coordination or attention when fatigued
- Notice patterns in daytime sleepiness and quality of sleep at night – adjust routines accordingly
- Seek a caregiver support group to help you cope with stresses and the practical aspects of Parkinson's disease
- Seek professional counselling to provide strategies for managing mood

(Riva, Smith, Xie, & Weintraub, 2014; Sagna, Gallo, & Pontone, 2014)

Contact PSBC for information about their free short-term counselling services 1-800-668-3330 or counselling@parkinson.bc.ca.





SLEEP DISTURBANCES

Sleep-wake cycle disturbances are common in Parkinson's disease; in some cases, they may predate a Parkinson's disease diagnosis. They include:

REM sleep behavior disorder. A condition in which people act out their dreams during sleep. This is characterized by loss of normal skeletal muscle tone during REM sleep with prominent motor activity and dreaming. This can be violent and threatening to the caregiver as a bedmate.

Restless Leg Syndrome. An overwhelming desire to move legs, and uncomfortable, tingling, itching, burning, or throbbing sensations. Happens when resting, sitting, and/or lying down.

Daytime sleepiness. Sleepiness in the day becomes more prominent as the disease progresses and sleep-wake cycles become disrupted. Dopaminergic medication and poor quality night-time sleep can cause daytime sleepiness in Parkinson's disease.

Considerations for sleep

- Get exposure to adequate light and sufficient physical activity during the day
- Use a firm mattress
- Use a soft pillow that you can position for greater comfort
- Sleep with several pillows or raise the head of your bed 30° if you have difficulty with swallowing and drooling
- Ensure bed is at least 22" high and placed securely against wall
- You and your sleep partner may want to use separate covers
- Sleep in separate twin beds or separate bedrooms if REM sleep behaviour disorder is an issue
- Consult your neurologist or physician about medication that may be useful in the management of REM sleep behaviour disorder (e.g., Clonazepam or melatonin)
- A bedside commode, urinal or bedpan can be helpful for toileting
- Use a throwaway pad to protect mattress
- A trapeze bar above the bed can help the person sit up in bed or a pull rope at foot of bed can help the person with Parkinson's disease transfer positions
- Use sturdy chair or table or bedside rails for getting in and out of bed
- Use silk sheets to facilitate turning in bed; avoid flannel sheets and PJs
- Remove top sheet and use a lightweight comforter only
- Ensure there is a well-lit path from the bed to bathroom
- Establish good sleep hygiene and consistent bedtime/morning routines

Refer to PSBC's Sleep and Fatigue helpsheet for more information about sleep disorders.

(Howell & Schenck, 2015; Meyer et al., 2007; Schrempf, Brandt, Storch, & Reichmann, 2014; Suzuki, Miyamoto, Miyamoto, & Hirata, 2015; Wijemanne & Jankovic, 2015)

More information can also be found in *A Guide to the Non-Motor Symptoms of Parkinson's disease* booklet by Ronald Postuma and Christos Galatas (Feb 2012); available through PSBC.



CHAPTER 4:

ACCESSING SUPPORT FOR PEOPLE WITH PARKINSON'S

LEARNING OBJECTIVES

- *Managing a care team*
- *Resources for*
 - *Exercise*
 - *Travel*
 - *End of Life*
 - *Respite & Home Care*
 - *Housing Options*
 - *Professional Caregiving Considerations*

As Parkinson's disease progresses and medication regimes are adjusted, people's abilities may fluctuate. The changes that occur between different stages are fluid. This section contains some considerations for early, middle and advanced Parkinson's, as well as respite, home care and housing options. You may need these resources at different times in the disease process.

It is important to consult your neurological and/or general practitioner as you notice changes in the behaviour or ability of your loved one.

MANAGING A CARE TEAM

CAREGIVER, AS CHIEF EXECUTIVE OFFICER (CEO)

What if you compared your caregiving duties to that of a CEO of a small business?

What would your mission statement be?

- Is the goal to stay at home as long as possible? Do you want to continue to travel abroad? Or maintain a regular exercise habit?

Who would be on your board of directors?

- Trusted advisors, such as family members and friends, to help come up with ideas and make decisions on care plans.

Will you hold regular meetings?

- A CEO regularly meets with the board of directors to discuss new directions in care, new symptoms that need to be managed or change in dependence.

Will you take scheduled and regular time off?

- Just like you would book time off in advance from a company, as a caregiver you are entitled to time off. Book longer time off well in advance (e.g., a golf weekend away from your spouse) so that you can make the necessary care arrangements. Book small periods of time for respite/relaxation/recreation regularly (e.g., every Tuesday from 1-2:30) so that you plan to have consistent help during that time.

(Imke, Hutton & Loftus, 2012)



BUILD A CARE TEAM

Develop healthy relationships with your loved one's healthcare team; understand each healthcare professional's role and when/how to access them when their services are needed. The Parkinson specialist team can include:

- Movement disorders specialist, neurologist or general practitioner
- Nurse/nurse practitioner
- Physiotherapist
- Occupational therapist
- Speech language pathologist
- Pharmacist
- Social worker/counsellor
- Dietitian
- Psychologist/psychiatrist

(Patel & Chang, 2014; Travis, 2007; Vernon, 2009; Wiener, 2010)

Include family and friends who are willing to help in any way as part of your care team. **As a primary caregiver, delegate responsibilities according to ability – make a list of who is good at (and willing to do) what and when they are available.** Hire a team of professionals (when finances allow) to fill in the gaps. Caregiving is about knowing what needs to be done and who to call to do it. Learn to delegate.

Learn more on this topic by reading PSBC's helpsheet *Your Healthcare Team and How to Access it*.

ORGANIZE INFORMATION

Create your own system where you and your loved one can keep track of doctors, other members of your healthcare team (e.g., therapists), medications, supplements, hospitals and care facilities, medical bills, and insurance paper work. Have a calendar to track medical appointments, activities and other commitments all in one place. It may seem like an overwhelming amount of information at first, but your own system can help you stay on top of it. Designate a filing cabinet drawer or a binder to document and file information so you can keep everything in one place.

RESOURCES FOR YOPD

Compared with older people who are often relieved when the diagnosis is finally made, younger people may have greater difficulty adjusting to the Parkinson's diagnosis. People with YOPD (Young Onset Parkinson's Disease) tend to experience a slower progression of their disease, live longer with their condition, and experience motor fluctuations earlier. They may also not need treatment initially, but will need good medical care throughout their Parkinson's journey.

Being a spouse of someone with YOPD has its own challenges. While you both may continue to work, take care of children and your own parents, being a caregiver to someone with YOPD may mean creating more space in your daily life to care for this loved one. It is therefore important that you start pulling family members, friends and healthcare professionals together to make that support network strong and effective.

CONSIDERATIONS FOR NEWLY DIAGNOSED AND EARLY STAGES

Being diagnosed with Parkinson's can bring about a swarm of emotions, such as relief of knowing what your symptoms mean, being scared for the future, feeling angry and sad. Not only is the person diagnosed experiencing the shock, but you, as a family member or friend, may also be having your own rollercoaster of emotions. As we have come to understand, Parkinson's disease is a family affair. Here are some things worth considering when caring for someone with Parkinson's.

THE BENEFITS OF EXERCISE

In the early stages, only 12-15% of persons with Parkinson's disease are referred to physiotherapy, and do not ask how much exercise, or what type of exercise to do. This is because people may not be self-aware of their declining function during daily activities. **However, the early stages of Parkinson's disease, when symptoms first surface, is a sensitive period where exercise can slow the neurodegenerative process, improve body awareness, and self-correct everyday movements that have become smaller and slower.**

As a caregiver, you have a vital role to support (and convince!) your loved one to get active and participate in exercise as soon as possible.

Parkinson's symptoms can cause some people to reduce the amount of activity they complete because they are uncomfortable, in pain, or think they cannot do the same activities anymore. Promoting physical activity in your loved one may alleviate or prevent secondary complications – such as cardiovascular disease, depression, isolation, frailty and obesity, and also offer Parkinson-specific benefits. For example, exercise has a positive influence on sleep disturbances and constipation, can postpone cognitive decline, and may address changes in mood.

Getting your loved one involved in a class or group training environment can significantly improve their quality of life. Interaction with fellow persons with Parkinson's disease helps people to better accept their disease, improves self-efficacy and supportive social connection.

Principles for exercise and physical therapy in Parkinson's disease:

1. It needs to be intensive activity to maximize brain changes
2. It needs to be complex activity to promote greater brain change
3. Activities that are rewarding increase dopamine levels and therefore promote learning/relearning
4. Dopaminergic neurons are highly responsive to exercise and inactivity ("use it or lose it")
5. Where exercise is introduced at an early stage of the disease, progression can be slowed

(Fox et al., 2006)

For more resources on exercise, visit Parkinson Society British Columbia's website at www.parkinson.bc.ca/activeliving or call 1-800-668-3330.

CONSIDERATIONS FOR MID-STAGES

Parkinson's disease (PD) is a progressive disorder, and the rate of progression varies tremendously from one person to another. As a caregiver, try not to predict problems; instead, be prepared for changes that are likely to occur over time. While medications may significantly reduce symptoms in the first few years of the illness, physical abilities will decrease and PD symptoms will increase as the years go by. People caring for someone at this stage of the disease may notice the following:

- **Inconsistent response to medications:**
Appearance of "on/off" fluctuations in response to levodopa is common. Fatigue can also be an issue. This makes it hard to plan activities, as you cannot predict physical capabilities, and Tuesday may be different than Wednesday. Caregiver flexibility is important!
- **Mood and cognition changes:**
Changes to how the person feels, thinks and reasons may become more problematic than the motor symptoms of the disease (how the person moves), for both you and the person with PD.
- **New safety considerations:**
If symptoms begin to significantly affect mobility, memory or thinking skills, it may be time to consider if it is still safe for the person with PD to perform tasks that he or she once did easily as part of the daily routine. For example, driving an automobile may become too risky, for your own family's safety or that of others on the road. Giving up driving is an enormous loss of independence to many people and can create a new burden for the caregiver.
- **Physical symptoms that are better relieved with non-medication therapies:**
Many people find that exercise groups and physical or occupational therapy help with motor symptoms of PD. For communication problems, you might also seek a referral for specialized speech therapy. Don't discount the importance of exercise; findings have shown that people who begin regular exercise early in the disease experience a slower decline in quality of life.

- **Role conflicts:**
People with Parkinson's and primary caregivers rarely adjust to living with PD at the same rate! You might need to adjust household and lifestyle responsibilities and habits. For example, should you start paying the bills? Is it time to hire someone to do the yard work? This can be a hard transition, and the very person you're trying to help might resent these changes.
- **Early signs of caregiver fatigue:**
After increasingly "taking the lead" in your relationship (with no end in sight), it is understandable if you regret that life is not turning out the way you expected or hoped. As the disease progresses and your role as caregiver evolves, you will have to come to terms with the disease again and again.

(Parkinson's Foundation, 2017)





TRAVEL AND TRANSPORTATION ACCOMMODATIONS

- Schedule travel for a time of the day when the person with Parkinson's is well-rested and medication is likely working
- For longer trips, be realistic with respect to stamina
- Build in rest-days for the person with Parkinson's before and after the travel day
- Get a letter from your loved one's doctor and/or pharmacist about their medication needs, complications and their contact information. Ask about recommendations for care in the area you are traveling to. Get an Aware in Care kit from PSBC
- Pack a bag: pill box, extra medication (in their original bottles), identification, liquids, snacks, incontinence pads
- Consider dressing in layers and having an extra lap blanket or shawl
- Ensure you have travel insurance that covers emergencies, pre-existing conditions/medications

Car travel

- Align the person with Parkinson's body close to the car and have them turn to sit down safely before moving legs into the vehicle
- Consider using a slippery fabric on the seat to make it easier for the person with Parkinson's to position themselves
- Consider a travel walker or transport wheelchair that is lighter and can be placed in the backseat or trunk easily
- Meet with a physical therapist to determine if there is any adaptive equipment that may be helpful (e.g., portable handle, seat belt extender)

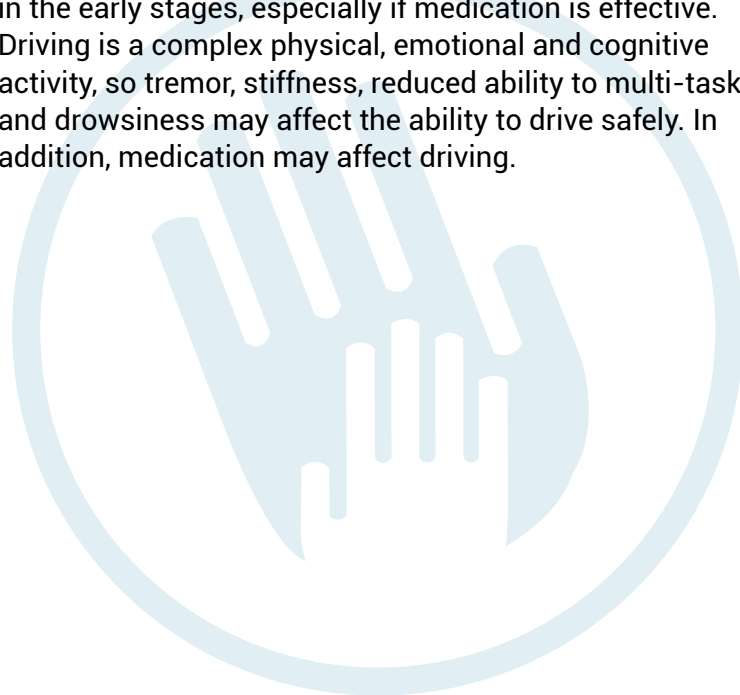
Shared transit services, such as HandyDART, are a great option for appointments – but take the time to learn their processes for scheduling (which often needs to occur weeks in advance). Pick-up/drop-off services often have a wide window, so be prepared for some waiting time. Call your location public transit operator and ask them about their paratransit or shared transit services.

Air travel

- Travel non-stop if you can
- Consider requesting wheelchair services and luggage lifts at the airport
- Take advantage of early boarding
- Ask for the front seats and/or bulkhead to avoid crowded aisles
- Note the proximity to washrooms
- Check as many bags as you can, but keep insurance and necessary medical supplies in your carry-on
- Drink lots of water, get up and walk the aisles periodically, if you are able to, and stretch

Driving

When someone receives a Parkinson's diagnosis, they ask "Can I still drive?" Many people can continue to drive in the early stages, especially if medication is effective. Driving is a complex physical, emotional and cognitive activity, so tremor, stiffness, reduced ability to multi-task and drowsiness may affect the ability to drive safely. In addition, medication may affect driving.



TIPS *for safe driving*

If you have concerns about a person's ability to drive safely:

- Find the time to drive with your loved one and assess their driving skills objectively
- Encourage your loved one to take a self-assessment or visit a medical professional for a driving-fitness check up
- Bring up any concerns on an agreed upon time, not while in the car
- Describe your concerns in specific behavioural terms, avoid blaming, and bring up the risks of unsafe driving if your loved one does not hear your concerns
- Your loved one may be upset or defensive about their driving; be sensitive and ask how they are feeling

For more information on Travelling and Driving, see the Daily Living section of PSBC's website at www.parkinson.bc.ca/resources.

CONSIDERATIONS FOR ADVANCED STAGES

Parkinson's disease is considered advanced when the person is no longer physically independent. Serious problems with both mobility and/or cognition impair the person's ability to complete activities of daily living, and you may be seeking additional support in providing care. You may also want to start planning for the future and speak to your loved one about their wishes for end-of-life care.

END-OF-LIFE AND PALLIATIVE CARE

At the end of life, each story is different. End of life is defined as that time period when healthcare providers would not be surprised if death occurred within 6 months. **End-of-life care is supportive and compassionate care that focuses on comfort, quality of life, respect for personal healthcare treatment decisions, support for the family, and psychological, cultural and spiritual concerns for dying people and their families. Palliative care is specialized medical care for people with serious illness – whatever the diagnosis.**

Care can be provided wherever the client is living: at home, in hospice, in an assisted living residence or a residential care facility. Services aim to preserve an individual's comfort, dignity and quality of life as their needs change, and to offer ongoing support for family and friends.

In British Columbia, there is no cost for community nursing services or community rehabilitation services if you are receiving care at home. Some medications and palliative supplies and equipment are available free of charge for eligible patients through the BC Palliative Care Benefits Program. In addition, there is no cost for home support services if you are enrolled with the BC Palliative Care Benefits Program. If you require publicly subsidized residential hospice palliative care, you will pay a fixed daily rate of approx. \$35-45 per day.

For those who are receiving long-term residential care services, when first admitted to a residential care facility, a person's immediate needs are assessed and a transitional care plan is made. Usually within six weeks of admission, the care is reviewed with the person's family as the person settles in to the new environment.

End-of-life and palliative care services available to clients include:

- Care coordination and consultation
- Pain and symptom assessment and management
- Psychological care
- Community nursing services
- Home support
- Respite for caregivers
- Residential hospice care
- Loss and grief support for family caregivers
- Access to specialized prescription medication, supplies and equipment

More information available at:

- Government of BC - Palliative Care Benefits Program (Plan P)
- BC Palliative Care Drug Plan: Contact Health Insurance BC at 1-800-663-7100
- For Medical Supplies and Equipment contact your local Home and Community Care office



COMPASSIONATE CARE BENEFITS

The Government of Canada pays compassionate care benefits to persons who have to be away from work temporarily to provide care or support to a family member who is gravely ill with a significant risk of death within 26 weeks. Care or support to a family member means: providing psychological or emotional support, or arranging for care by a third party, or directly providing or participating in the care.

More information on Compassionate Care benefits can be found in the Employment Insurance Benefits section of the Government of Canada's website at www.canada.ca/en/services/benefits.html.

LOSS AND GRIEF

Caregivers may feel loss at many stages of the disease progression. Loss can be associated with the presence of symptoms such as agitation, depression, or other behavioural changes. Feelings of loss can also be associated with the wishes you once held for these years of your life.

Grief is a natural reaction to feelings of loss and this process can be ongoing for those caring for a person with a progressive degenerative disease. Anticipatory grief may also arise in the advanced stages of the disease when you may grieve the loss of the person with Parkinson's "former self".

All of these feelings, and more, are completely normal. Self-care and the time to work through feelings of loss and grief is an important coping strategy. **Care for yourself with the same compassion you care for your loved one.**



TIPS *for anticipatory grief*

- Set aside some time to understand how you are feeling and what is happening
- Talk to someone (friend, family, support group, professional) about your feelings
- Acknowledge and grieve each loss as it happens
- Acknowledge the emotions (fear, anger, sadness) triggered by loss; know these are normal
- Break the source of stress into smaller pieces and develop coping strategies for each part
- Ensure your health needs are met

For more information on caregiving, grieving and loss, see the Caregiving and Family section of PSBC's Resources at www.parkinson.bc.ca/resources.

PREPARING FOR A MEDICAL APPOINTMENT

COMMUNICATING WITH HEALTHCARE PROFESSIONALS

Sometimes communicating with healthcare professionals can be tricky. People are busy coordinating healthcare plans and patient inquiries. To get the most out of your medical appointments, apply the principles of the P.A.C.E. framework:

P - present detailed information about how you are feeling

A - ask questions if desired information is not provided

C - check your understanding of information that is given to you

E - express any concerns about the recommended treatment

PLANNING FOR MEDICAL APPOINTMENTS

Respect your healthcare professional's time. Come prepared to the appointment; bring the top 3 priorities for the person with Parkinson's disease, with 1 major issue and 2 minor ones. If you have a lot to discuss, consider booking more than one visit to cover all issues.

TIPS *for healthcare appointments*

- Clearly explain what you hope to get out of this appointment
- Have a list of questions in order of importance
- Bring written information regarding medication and symptoms
- Check prescription bottles for needed refills before you go
- Note any changes in living situation, cognitive ability, mobility level, mood disturbances and/or psychosocial needs
- Note if your loved one is receiving any new care (e.g., speech therapy)
- Bring a pen and paper, or a tape recorder, to ensure you get all the information given to you

Build a good relationship with the healthcare professional and understand how they can best help in the person with Parkinson's care. **Ensure you and your loved one understand all recommendations and follow-up plans before you leave the healthcare professional's office.** If your healthcare professional is starting the person with Parkinson's disease on a new medication and/or therapy, consider asking the following questions:

- Why is this needed?
- How soon can we expect to see improvements?
- What side effects are associated? Any risks?
- Are any interactions possible with other medication/treatments?
- Is the generic version of the medication any different from the brand name?
- Do I need to seek out a specialist referral for this?
- Are any follow-ups necessary?
- What will happen if we choose not to do this?
- Do diet and/or exercise have any effect?
- What other options are available?
- What do you hope the person with Parkinson's disease will get out of this?

TRACK MEDICATION AND KNOW SIGNS OF WEARING OFF

As a caregiver, you can watch for symptoms that may indicate your loved one is experiencing “wearing off” of their medication. You and your loved one can track his/her symptoms and medication schedule, noting whether the symptoms tend to appear/worsen before the next levodopa dose is scheduled, and whether they improve after levodopa medication.

It is not always easy to remember when medication is taken, how long benefits last, and what the side effects are. A diary can include time of day medication is taken, timing of meals/snacks around medication, time of day when there is good symptom control, which symptoms appear when (day vs. night), symptom severity, and any side effects (i.e. dyskinesia, anxiety, fatigue).

If necessary, speak to your loved one's physician who may be able to address wearing off by:

- Adjusting the timing and/or dosage of levodopa medication
- Changing the current levodopa therapy (i.e. active vs. controlled release) to decrease “off time”
- Adding additional medication or combinations of medication to ensure symptoms are controlled as best as possible

For more information on these topics, see the Daily Living section of PSBC's Resources at www.parkinson.bc.ca/resources.





ACCESSING OUTSIDE HELP: RESPITE

When it is time to take a break, respite services may be beneficial to you. Respite is a period of short-term relief from care duties. Short-term care, or respite, for your loved one allows you to take a break from the caregiving routine. It also may help you care for the needs of your loved one as their Parkinson's is progressing, enabling him/her to stay home longer. Respite services can come in many different forms. Formal respite may look like a temporary care facility, while informal respite could be personal arrangements with friends or family. Whatever the form, be prepared to train and educate a few people who are willing to replace you to provide respite care.

MAINTAINING HEALTHY BOUNDARIES

It is important to remember that you have needs too, and it is important to set limits in order to encourage your own self-care. Where do you draw the line and say "I can only do this much"?

TIPS *for creating boundaries of care*

- Evaluate your own abilities and time and be realistic about what you can do and what you will do
- Set boundaries and stick to them
- Learn to say no to demands that are unreasonable, unmanageable or inappropriate
- Prioritizing is important; we can't do everything!

Also keep in mind that although you can help, the person with Parkinson's may enjoy some independence and find other ways to manage their own needs.

WHEN FURTHER CARE IS NEEDED

As the disease progresses, there may come a time when you need a break or you alone are unable to provide safe and effective care at home. At this point, a transition needs to occur; whether it is getting additional help in the home, community supportive housing or admittance to long-term residential care. **There are benefits to all these models of care, and this does not mean you are no longer a 'caregiver', it simply changes the way in which you provide care to your loved one.** It is important to note that people call these decisions, especially the transition out of the home, the hardest decision they've ever had to make. Ensure you seek support in managing your own feelings (i.e., guilt) that may arise during this transition.

If you are looking for publicly funded services, contact your local health authority to request an assessment for home and community care services. When you call, you need to tell them that you are looking for services for a senior in their home, or you are looking for nursing homes, assisted living, or other supportive housing. They will want to know the address of the person needing care. Then they will put you through to intake, where intake will ask you for some information, and hopefully set you up with a case manager, who will come to the house to do the assessment. A health professional can also make a referral on your behalf and you will be given a case manager. If someone is in hospital, assessments are done in hospital, and services can be arranged from hospital.

IN-HOME SUPPORT (I.E., HOME CARE)

Home care services are not covered by the Canada Health Act, although all provinces provide home care services. In BC, planning and delivery of health services is carried out by five Health Authorities, depending on where you live in the province.

There are a number of healthcare services that are made available to you. BC's Continuing Care Programs Regulation identified programs that are prescribed as continuing care programs under section 3 of the Continuing Care Act by the Ministry of Health:

- Home support services (medication management, wound healing)
- Adult day services
- Meals programs (including Meals on Wheels and Congregate Meal Programs)
- Continuing care respite services
- Continuing care case management
- Continuing care residential care services
- Short stay assessment and treatment centres
- Home oxygen programs
- Assisted living services
- Home care nursing
- Community respite services (including Short-term Residential Care, see below)

If you are interested in finding out more about the home health services that can be made available to you and your partner with Parkinson's call your local health authority's Home and Community Care office.

Fraser Health:

W: www.fraserhealth.ca

T: 1-855-412-2121

Interior Health:

W: www.interiorhealth.ca

T: 250-469-7070

Island Health:

W: www.viha.ca

T: 1-888-533-2273

Northern Health:

W: www.northernhealth.ca

E: hello@northernhealth.ca

Providence Health:

W: www.providencehealthcare.org

T: 604-806-9090

E: communications@providencehealth.bc.ca

Vancouver Coastal Health:

W: www.vch.ca

Vancouver 604-263-7377

Richmond 604-278-3361

North Shore 604-986-7111

(Ministry of Health, 2015a, 2015b, 2015c; Imke, Hutton, & Loftus, 2012)

The following respite options can be found in BC.

ADULT DAY PROGRAMS

Adult day programs are community-based day-long or half-day social and recreational programs provided in a group setting. Programs may include exercise, meals, snacks, assistance with toileting/eating/mobility, health education and promotion, counselling, podiatry and/or blood pressure clinic, socialization, peer support, caregiver counselling and education, etc. Health authorities may charge a nominal rate, no more than \$10, which can be waived if necessary.

SHORT-TERM RESIDENTIAL CARE

For short-term residential care services (less than 3 months), residential care facilities may have specific rooms set aside for these stays. There are different forms of short-term residential care.

- Respite care provides caregivers a period of relief and their loved one a period of supported care
- Convalescent care provides persons with defined/stable care needs a supervised environment for reactivation or recuperation following discharge and/or acute period of care
- Residential hospice care provides persons support, comfort, dignity and quality of life in their final days

For short-term residential care you will pay a fixed daily rate of approx. \$35-45 per day according to the Government of British Columbia (2018). You may be eligible for a reduced rate if you have serious financial hardship.

COMMUNITY/RESIDENTIAL HOUSING OPTIONS AND CARE

It is often seen as a balancing act in the healthcare system to provide timely access to housing options (especially residential care) when needed and in a manner that respects the preferences and goals of the person and their family.

In British Columbia, families are asked to identify their preferred facility or location. While this is accommodated to the degree possible, there is an expectation that the client will accept the first "appropriate bed" available and agree to occupy the bed within 48 hours, with the option of transferring to another site later if they wish. What constitutes an appropriate bed includes factors such as the facility's ability to meet the specific needs of the person, reasonable distance for a spouse or family to visit, and the same community or geographic area.

This situation may be distressing if you are asked to make important housing/care decisions on very short notice. This makes it important to have a discussion early around housing options and investigate ones in advance that suit the values, preferences and care situation of you and the person you are caring for.

According to British Columbia's Continuing Care Act, there are 3 main types of housing options: Independent Housing, Supportive Housing and Long-Term Care Facilities.

INDEPENDENT HOUSING

Examples of independent housing options may be: own home, condo or townhouse, seniors housing, retirement communities, independent living, adult communities, retirement villages.

These options are for persons who are fully independent in their day-to-day activities who live in their own dwelling and have their own furnishings. Some options may offer amenities, such as housekeeping services, meals and entertainment, for a separate fee. Healthcare supports are provided by home care and/or the family physician in a similar way to those living in their own homes. Arrangements are made for these housing options independently (i.e., on your own). You can consult your local health authorities Home and Community Care office for guidance on available independent housing options in your community.



SUPPORTIVE HOUSING

Examples of supportive housing options may be: assisted living, retirement residences, seniors lodges, supportive housing, enriched living, personal care homes, family care homes.

These options provide a semi-independent setting where each person has their own room or apartment, and may choose to participate in congregate activities. In a supportive housing setting, services that are provided by care aides and recreation coordinators may include: assistance with medications and personal care, 24-hour support and response system, meals, housekeeping and activities.

Nursing, medical care and rehabilitation services vary, but most supportive housing options provide services in a similar way to those living in their own home. These options include a mix of private options (personal or family arrangements) and publicly subsidized options (coordinated by the health system).

LONG-TERM RESIDENTIAL CARE FACILITIES

Examples of long-term residential care facilities may be: residential care, dementia cottages, long-term care, nursing homes, group homes, complex care facilities, special chronic care units or hospitals, and assessment, treatment or day hospitals.

Long-term residential care provides care to people who are no longer able to safely live at home. Chronic care units or hospitals provide care to people who require long-term hospitalization (due to chronic illness or functional disability), but do not require the resources of acute/psychiatric/rehabilitative hospitals. Support services include 24-hour coverage by professional nursing staff and on-call physicians. Specific staffing requirements and standards have been established through regulations/guidelines, to improve safety and the quality of care.

Assessment and treatment centres and day hospitals provide short-term diagnostic and treatment services in a special unit within an acute care hospital setting.

The aim of these facilities is to assist people to achieve optimal function and independence. These facilities may include beds for inpatient assessment and treatment, day services, and/or outreach capacity.



PREPARING PROFESSIONAL CAREGIVERS

It is important the person/agency/organization you hire to care for someone with Parkinson's disease is familiar with the disease process so they can better understand and relate.

TIPS *for preparing professional caregivers*

- Provide the hired caregiver with information on Parkinson's disease. For more information, visit PSBC's website: www.parkinson.bc.ca.
- Provide the hired caregiver with information on the person with Parkinson's disease themselves, not only their disease history and other medical information, but their preferences, hobbies, occupation, and daily routines. What are they able to do independently?
- Provide the hired caregiver with information on the household routines (e.g., wake/sleep times, when/where are meals served, etc.).
- Review emergency procedures and provide the hired caregiver with emergency contacts.
- Collaborate on making a care plan. Discuss what tasks the hired caregiver will be responsible for and any associated timelines.
- Provide clear instructions/procedures for regular care (e.g., bathing) and potential problems (e.g., wandering).
- Discuss any boundaries (e.g., visitors while working, smoking on the property).
- Regularly check in with the hired caregiver, especially since people with Parkinson's needs change over time as the disease progresses.
- Seek feedback from the hired caregiver on how the job is going, any concerns and/or suggestions for improving care.
- Understand professional boundaries – a hired caregiver should not be involved in family or financial decisions.

Questions to consider when hiring a professional caregiver:

- What is your education/training?
- Are you able to provide medical (e.g., nursing, rehab) and non-medical services (e.g., bathing, mobility assistance)? What are each of these services and the associated fees?
- Availability? Do you provide 24-hour care? On call care? Is it the same person providing care every time?
- Can you provide transportation services?
- Are you licensed to provide home care?
- Do you have liability insurance?
- Will you perform an assessment and create a care plan with me? How will we update that care plan?
- How do you bill? What is the billing schedule (e.g., per day? Per hour?)?
- Do you have a substitute in case you are unable to make it (e.g., due to illness)?
- How do you document the care provided?
- When can you start providing care?
- Can you provide references/background check?

(Imke, Hutton & Loftus, 2012; DeGraff, 1988)

For more information on this topic call toll-free 1-800-663-7867 or visit Government of BC's Care Options and Costs at www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care



CHAPTER 5: PREPARING FOR THE FUTURE

LEARNING OBJECTIVES

- *Personal planning*
- *Estate planning*

We often put off getting our affairs in order and making necessary legal documents for future planning – we know it is a good idea but we don't feel the immediate need and/or it seems too complicated.

Living with a progressive disease like Parkinson's means you have a compelling reason to plan for the future. This section can assist you with making arrangements in a timely and realistic fashion. **The sooner you start, the more options you will have and the more control. Plans can always be cancelled and/or revised if necessary.** Planning is more difficult and less effective in the midst of a crisis.

Try to keep your plans clear and straightforward so they are understandable to those involved. Keep in mind that legal planning documents should indicate:

1. Who the document belongs to
2. Who is appointed and in what roles
3. What authority is covered
4. When the document is in effect

The reasons people engage in future planning are:

- To have a say or control over how things are handled when you cannot do it yourself
- To ease the burden on your spouse, family and friends
- To avoid the need for government or other parties to be involved in your personal and private affairs

There are many types of planning – retirement planning, financial planning, and tax planning. These are not the focus of the topics under future planning but they are related and you will want to provide others with details of such plans.

For more information on these topics, see the Legal Series section of PSBC's resources at: www.parkinson.bc.ca/resources#legal.

PERSONAL PLANNING

Personal planning is a broad term for making arrangements while you are alive in the event you need assistance in one or more life areas: healthcare/advance care planning, personal care, legal affairs and/or financial affairs. Having a Will and "everything in joint names" is not sufficient. For example, eligibility for subsidized health and personal care services (e.g., where you live) may depend on your income tax return. Someone may need authority to access your tax information.



WHERE TO GET ADDITIONAL HELP?

The Nidus Personal Planning Resource Centre and Registry is a non-profit, charitable organization devoted to personal planning. Nidus has a lot of information on planning as well as the legal forms required. Nidus (www.nidus.ca) provides training and support to community groups such as Parkinson Society British Columbia. You can contact the staff of PSBC for help and guidance at 1-800-668-3330 or info@parkinson.bc.ca.

WHAT IF I DON'T DO ANY PERSONAL PLANNING?

If you are incapable and you did not authorize the person you want to make healthcare decisions on your behalf, a healthcare provider will select someone from a ranked list in the Health Care (Consent) and Care Facility (Admission) Act. This person is called your Temporary Substitute Decision Maker (TSDM). A spouse and next-of-kin are top of the list, followed by a close friend and then an in-law. The Public Guardian and Trustee (a government official) is the last resort. A TSDM does not have as much authority as a representative you name in a Representation Agreement.

If you are incapable and you did not make your own arrangements to authorize someone to manage your financial affairs, then a spouse or family member may have to apply to court to become your Committee of Estate (guardian for finances). This procedure takes 3 to 4 months and costs \$5,000-\$7,000. In some cases, the Public Guardian and Trustee (PGT) will take over management of the adult's financial and legal affairs (if the adult can afford the PGT fees).

Help yourself and those who care about you by getting your plans in place. This is perhaps even more important as a caregiver than someone who has Parkinson's.

Personal Planning steps:

1. Determine which "path" (i.e., future path or need help today path) fits your situation.
2. Learn more about the legal documents available for your path and discuss with your spouse, family/friends.
3. Complete your legal documents and organize practical information.
4. Safe keep your information and documents, and communicate with others.
5. Review your plans and have ongoing discussions as you learn more about Parkinson's.

1. DETERMINE THE PATH FOR YOUR SITUATION

- A. Future Path: for adults who make their own decisions now and understand the nature and effect of making legal documents to be used in the future if they are not capable
- B. Need Help Today Path: for adults whose mental capability to understand is currently in question. This might be due to advanced dementia, a brain injury or other conditions affecting their mental capability

2. LEARN ABOUT THE LEGAL DOCUMENTS AVAILABLE FOR YOUR PATH

A. Future Path

There are two key legal documents adults (who are considered capable) can make in case of incapacity and for end-of-life

I. Health and personal care matters

- Representation Agreement Section 9 (RA9) is used for all health and personal care matters, including refusing life support; and
 - The person you appoint is called your representative. It is a good idea to name someone as an alternate representative
 - No legal professional is required to draft a RA9. The form can be obtained from Nidus

II. Financial and legal affairs

(only make one of the following)

- Enduring Power of Attorney (EPA) is used for all financial and legal affairs
 - The person you appoint is called your attorney (NOT lawyer). It is a good idea to also name someone as an alternate attorney
 - It is recommended to use a legal professional (lawyer or notary public) to draft an EPA
 - If you own assets in other provinces, the United States or other countries, be sure to discuss this with legal and/or financial professionals
- OR**
- Representation Agreement Section 7 (RA7 F+L) is used for routine financial and legal affairs – instead of an EPA

- Most people will make an EPA, especially if they have a spouse and/or dependents
- No legal professional is required to draft an RA7 F+L. The form can be obtained from Nidus

Other legal documents that adults who are considered mentally capable can make (optional):

- Advance Directive
 - Written instruction to give or refuse consent to certain healthcare matters. It must be made when the adult is capable of understanding the nature and effect of what it covers
 - It does not cover personal care decisions, arrange for a second opinion, or deal with unexpected/challenging circumstances. For this, use the RA9
 - There are a number of requirements that must be followed and it is advised to seek help from a medical source, not a legal professional
 - Ensure a copy of your Advance Directive is provided to your representative and alternate representative, named in the RA9
- Organ Donation
 - Register with BC Transplant at www.transplant.bc.ca
 - The BC Transplant registration lets healthcare providers find your wishes but it does not help inform your family/friends about your wishes in advance
- Body Donation
 - You must complete a consent form and register with the UBC Department of Medicine Body Donation Program (www.cps.med.ubc.ca/bodyprogram)
 - The Body Donation Program does not inform your family/friends in advance about your wishes
- Trusts for Financial Assets
 - Different kinds of trusts allow control over certain financial assets and to help a family member who has a chronic illness or disability
 - Living Trust (Inter-vivos) means that it is in effect/operation while you are alive
 - Testamentary Trust comes into effect when you die
 - Contact a lawyer (not notary public) who has specialized experience in this area

Other non-legal documents that adults who are considered mentally capable can make (optional):

- Living Will or advance care plan: wishes about care you do or do not want, your values and beliefs
- No-Cardiopulmonary Resuscitation: do not resuscitate (DNR) Order
- Medical Order for Scope of Treatment (MOST form): wishes about end-of-life care
- Levels of Care or Degrees of Intervention: for residential care

The above documents do NOT give legal consent in advance. No one else can fill these out on your behalf. If you use any of the above or another document to express your wishes, give it to your representative and alternate named in your RA9. It can guide them if they have to make decisions on your behalf. Review any wishes on a regular basis and update if necessary.

B. Need Help Today Path

There is one legal document adults can make, even when their mental capability to understand is in question, that covers all life areas (i.e., health care, personal care, financial and legal affairs).

The legal document is a Representation Agreement Section 7 (RA7). The RA7 is for adults who are not considered capable of making a RA9 or an EPA. No legal professional is required; Nidus has legal forms for the RA7.

What if my spouse/parent made an Enduring Power of Attorney while capable?

If there is an existing EPA but the spouse/parent is not capable of making a RA9, then the spouse/parent will make a RA7 H+P to cover the health and personal care matters. Nidus has a form you can use.

What if the doctor says my mother is incompetent of managing her affairs?

RA7 is for all adults, even when they cannot manage their own affairs and are not considered capable.



3. COMPLETE YOUR LEGAL DOCUMENTS AND ORGANIZE PRACTICAL INFORMATION

A. Future Path

The Nidus website has free Representation Agreement legal forms you can use for making a Representation Agreement Section 9 (RA9). It also has an Enduring Power of Attorney (EPA) checklist to help you prepare for meeting with a legal professional. You will also find fact sheets on Role of a Representative and Role of an Attorney. There is also information on Advance Directives and Organ Donation as well as informal documents. Go to www.nidus.ca > click on Future Planning.

B. Need Help Today Path

The Nidus website has Representation Agreement Section 7 (RA7) forms you can use. There is also information for those who will be named in the RA7. Go to www.nidus.ca > click on Caring for an Older Adult.

Gather the following information for those named in your legal documents:

Emergency contacts and emergency to-do list

- Do you have a pet that might need to be looked after in an emergency?
- Who has a spare key to your home?

Healthcare information

- List name and contact information of your physician, specialists, pharmacy, optometrist
- List prescription and other medications, allergies, naturopath and alternate treatments

Personal care information

- List personal habits and preferences – Early riser? Night owl? Favourite food/music/art
- List of hobbies, community events, spiritual activities, subscriptions (online or by mail)
- List of friends, family, community contacts (may need to be notified in emergency, at end-of-life, for memorial service)

Financial and legal information

- List name and contact information of financial institution, financial advisor, insurance company, tax preparer
- List income sources, bill payments (online or by mail), tax records, investments, property you own (vehicles, art, jewellery, real estate)

- List where original legal documents are kept, marriage/divorce papers, passport, Will, etc.

Other information about you

- Are you a veteran or in military service? Professional designations? Awards/distinctions? Memberships?
- Family history/ancestry, photos, etc.

4. SAFE KEEP YOUR DOCUMENTS AND INFORMATION, AND MAKE THEM AVAILABLE TO OTHERS WHO MAY NEED TO KNOW

Keep your original documents safe at home or give them to the representative to keep. It is not recommended to keep originals in safety deposit box or with legal professionals in case of urgent need. Make a copy for each person you named in the Representation Agreement and Enduring Power of Attorney. You can also register information and documents with Nidus' Personal Planning Registry as a back-up. Remember to let your spouse, family or friends know about your plans to avoid delay or confusion at end-of-life.

5. REVIEW YOUR PLANS AND HAVE ONGOING DISCUSSIONS

It is a good idea to review your arrangements at least once a year since your life as someone who is caring for a person with Parkinson's disease is constantly changing. If you register with the Personal Planning Registry, you can choose to receive an annual reminder by email. Talk about your wishes and preferences with your representative and alternate as well as your healthcare providers.

ESTATE PLANNING

Estate planning is about making arrangements for after death. Try to keep your arrangements straightforward and learn about the implications of different planning strategies.

You must be capable of understanding the purpose and nature of the documents and arrangements you are making as well as their effect in order to do estate planning. If someone is not considered mentally capable of making these arrangements, the Wills, Estates and Succession Act sets out a default scheme.

WHAT IF I DON'T PLAN FOR AFTER DEATH?

If you do not make arrangements for after death or your arrangements fail, the Wills, Estates and Succession Act sets out a default scheme for who can settle your affairs and how. It is more costly and time consuming for your spouse or family to settle your estate under the default scheme. The Public Guardian and Trustee is the last resort for settling estates and will only act as the administrator if you have enough money in your estate to pay their fees and the expenses for burial or cremation.

MAKE A WILL

A Will names someone as your executor who will have legal authority to make burial or cremation arrangements and settle your estate – money and assets you own at the time of death.

It is recommended to go to a legal professional when making your Will. It is a good idea to have an alternate executor as a back-up and talk to both these people in advance. Choose executors who are comfortable with forms and bureaucracies. It is common to name the same people in your Representation Agreement, Enduring Power of Attorney and Will.

A Will can appoint a guardian for minor children, but cannot appoint a guardian for someone 19 years or older (an adult), even if they have a disability. If an adult needs help with decision-making, they should make a Representation Agreement Section 7. In a wealthy estate, a Trust will appoint 'Trustees' who release money from the Trust according to the terms indicated. A Discretionary Trust can be used to protect a beneficiary's inheritance (e.g., if the beneficiary has a chronic illness or disability). Even if you have a very small estate, you should make a Will (if you meet the capability requirements).

Do not lose the original of your Will. You can make a copy for your executor and the person named as attorney in your Enduring Power of Attorney. You can register information about your Will ("Wills Notice") through the Wills Registry through the Vital Statistics Agency, BC Government (www2.gov.bc.ca/gov/content/life-events/death-and-bereavement/wills-registry) and store a copy with Nidus' Personal Planning Registry under 'Other Documents' (www.nidus.ca/?page_id=238).

EXPRESSING YOUR WISHES FOR BURIAL OR CREMATION

You can put your wishes for burial or cremation and the final resting place for your remains (where the remains are to be buried, interred or your ashes scattered) in writing. Your written wishes or instructions are binding, but only if they are written in:

- Your Will; or
- A preneed contract (a contract which allows you to pay in advance for a funeral and/or burial)

If you consented to Organ or Body Donation, the burial or cremation arrangements may be delayed. Your executor needs to know about any donations so they can keep in contact with the institution and be ready when your body is released.

If you do not leave specific instructions or wishes in the required form, your executor (named in your Will) has legal authority to make all the arrangements about burial and cremation. Clearly communicate these arrangements, which are often made well in advance, so there is no contradiction with other legal arrangements and to avoid duplication of payments.

Should I prepay my funeral?

You do not have to prepay for burial or cremation. Most people are eligible for the Canada Pension Death Benefit, which is intended to help with these costs. Your executor can pay the funeral bill out of your estate funds and apply for the death benefit to recover the costs for your estate. A membership with the Memorial Society of BC (www.memorialsocietybc.org) gives you a discount on burial or cremation when the time comes. They negotiate fees with funeral homes in most regions of BC.

No matter what arrangements you make in advance, the key is to make sure your executor knows about any prior arrangements. Often families do not know what you did in advance and then they proceed with new arrangements at full cost.

For more information about the funeral industry and 'preneed arrangements', go to Consumer Protection BC (www.consumerprotectionbc.ca/consumers-cemetery-and-funeral-homepage).



JOINT BANK ACCOUNTS

If you own certain assets jointly with right of survivorship, when you die, the title or ownership will generally go directly to the surviving owner(s). For example, spouses who have joint bank accounts and own vehicles and real estate jointly.

A joint account is not necessary for someone to help you manage your finances. If you make an Enduring Power of Attorney or Representation Agreement Section 7 with routine finances, the person you name will be able to help you manage your bank account if you cannot do it yourself. A single adult may think, or be advised, to add their son or daughter to their bank account for convenience. It is NOT recommended as standard practice today. The money in the account belongs to you and when you add someone else (other than a spouse) that person has equal access to your money. There are no safeguards in a joint account for you.

When you die and the financial institution is notified, your account will be 'frozen' to protect your money. Your regular account is changed to an estate account, which your executor can access. The funeral (burial or cremation) bill can be paid; financial institutions just need the original bill in order to make payment directly to the funeral company. If paid out of pocket by a family member, the executor can reimburse these expenses from your estate.

Issues an executor will deal with after your death

- Decisions about disposing of your body according to any written instructions
- Notifying family and friends of your death
- Obtaining the death certificate
- Applying for probate is a procedure to confirm the Will and the authority of the executor. Specific paperwork must be submitted to the Probate Registry of the Supreme Court of BC. Probate is not always required. It depends on a variety of factors, including the value of the estate at death
- Notifying institutions (government agencies, financial institutions, investment companies) of your death
- Applying for the Canada Pension Plan death benefit intended to help pay for burial or cremation costs
- Paying bills and outstanding debts, gathering any outstanding income, stopping bill payments or income contributions (such as pension benefits), selling property as needed (vehicles, real estate)
- Filing income tax returns on your behalf
- Distributing your property (money, valuable and sentimental items, personal effects) to beneficiaries according to your Will

This chapter was written by Joanne Taylor from www.nidus.ca



CHAPTER 6: CARING FOR THE CAREGIVER

LEARNING OBJECTIVES

- *The importance of self-care*
- *Stress management tools*
- *Cultivating resilience*

SELF-CARE

It is important to take care of your own needs. The role of caregiving can last many months and years, so it needs to be sustainable. Make self-care a habit early in the course of the disease. Caregiving is demanding on all levels – physical, mental, emotional and spiritual – so use the following tips to avoid burning out.

Health

Ensure you stay up to date with your own health needs. Visit your healthcare provider for a yearly physical, vaccination, mammogram, colonoscopy, and be diligent about your own prescription medication. If you find it difficult to remember your own appointments, get in the habit of scheduling your own separate doctor's appointments before/after your loved one's.

Nutrition

Poor nutrition can deplete your energy, so eat well. Ensure you get your daily dose of fruits and vegetables. You can look for pre-washed, pre-chopped and pre-packaged fruits and vegetables to reduce the amount of preparation and clean up. On busier days pack some snacks to take on the go – a handful of nuts, an energy bar or a sandwich. Don't forget to hydrate yourself with water.

Avoid fatigue: respite – relaxation – recreation activities

Caregivers need breaks too! Ask for help with care tasks so you can take some respite from caring, find something you enjoy that truly relaxes you (e.g., a bath, a walk, a book, a tea), and continue to participate in the activities you enjoy. You will have more energy and enthusiasm if your days include some things you enjoy. We need all 3R's separately; what do each of these look like for you?

Sleep

Think of sleep like you do gas in your car: the car can only go so far with the gas in its tank before refuelling, and you can only run so long without proper sleep. Give your body and mind the opportunity to rest on all levels.

Time management

Make daily and weekly to-do lists and prioritize tasks. Break larger tasks into small doable ones and do the important or difficult tasks first. Stick to routines. Delegate what you can and forget unnecessary tasks. Take a break or reward yourself for a job well done.

Connect with others

A good social network of support doesn't necessarily mean a large group. Find some informal support (i.e., support groups, family, friends) to help you with problem solving and preserve your own social outlets. Find joy in the time you spend with your loved one with Parkinson's.

A Caregiver's Bill of Rights

I have the right:

- To take care of myself. This is not an act of selfishness.
It will give me the capability of taking better care of my loved one.
- To seek help from others even though my loved one may object.
I recognize the limits of my own endurance and strength.
- To maintain facets of my own life that does not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things just for myself.
- To get angry, be depressed, and express other difficult feelings.
- To reject any attempts by my loved one (either conscious or unconscious) to manipulate me through guilt, and/or depression.
- To receive consideration, affection, forgiveness, and acceptance for what I do, from my loved one, for as long as I offer these qualities in return.
- To take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my loved one.
- To protect my individuality and my right to make a life for myself that will sustain me in the time when my loved one no longer needs my full-time help.
- To expect and demand that as new strides are made in finding resources to aid physically and mentally impaired persons in our country, similar strides will be made towards aiding and supporting caregivers.

(Horne, 1985)

CAREGIVER SELF-ASSESSMENT STRESS INVENTORY

Caregivers are often so concerned with caring for the person with Parkinson's ("care recipient") needs that they lose sight of their own well-being. Please answer the following:

During the past week or so, I have...

1. Had trouble keeping my mind on what I was doing	YES	NO
2. Felt that I couldn't leave my care recipient alone	YES	NO
3. Had difficulty making decisions	YES	NO
4. Felt completely overwhelmed	YES	NO
5. Felt useful and needed	YES	NO
6. Felt lonely	YES	NO
7. Been upset that my care recipient changed from his/her former self	YES	NO
8. Felt a loss of privacy and/or personal time	YES	NO
9. Been edgy or irritable	YES	NO
10. Had sleep disturbed because of caring for a person with Parkinson's	YES	NO
11. Had a crying spell(s)	YES	NO
12. Felt strained between work and family responsibilities	YES	NO
13. Had back pain	YES	NO
14. Felt ill (headache, stomach problems, common cold)	YES	NO
15. Been satisfied with the support my family has given me	YES	NO
16. Found my care recipient's living situation to be inconvenient or a barrier to care	YES	NO
17. On a scale of 1 to 10, with 1 being "not stressful" to 10 being "extremely stressful", please rate your current level of stress		
1 2 3 4 5 6 7 8 9 10		
18. On a scale of 1 to 10, with 1 being "very healthy" to 10 being "very ill", please rate your current health compared to what it was this time last year		
1 2 3 4 5 6 7 8 9 10		

To score:

- Reverse score questions 5 and 15. For example, a "No" response should be counted as "Yes" and a "Yes" response should be counted as "No".
- Total the number of "Yes" responses.

To interpret the score, chances are that you are experiencing a high degree of distress if:

- You answered "Yes" to either or both Questions 4 and 11; or
- Your total "Yes" score = 10 or more; or
- Your score on Question 17 is 6 or higher; or
- Your score on Question 18 is 6 or higher.

Next steps:

- Consider seeing a doctor for a check-up for yourself
- Consider having some relief from caregiving (discuss with the doctor or a social worker the resources available in your community)
- Consider joining a support group

(Epstein-Lubow, Gaudiano, Hinckley, Salloway, & Miller, 2010)

Communicate your feelings

Caregiving can be overwhelming at times. Letting this stress build up inside of you can have detrimental effects on your health. Express your emotions first!

Notice if you experience any changes in mood, signs of hopelessness, feelings of fear or changes in appetite/weight. Find a neutral party, such as a counsellor or caregiver support group, to honestly express your feelings about things you are uncomfortable discussing with family and/or friends. If you are uncomfortable talking to someone else, or have difficulty finding the time, try writing your thoughts, worries and concerns in a journal.

Problem solve

Be flexible and/or creative! Identify the problem and try to come up with three ways of how you could deal with it. Try something new and then be willing to try again.

Take charge

Focus on what you can control and alter your attitude around everything else. Focus on the optimist and change the patterns of automatic negative emotions, behaviours, reactions and beliefs. You can't change the situation but you can change how you feel about it and how you behave.

Set limits and stick to them

Set boundaries on your time and energy. What is the limit to your comfort level when providing care? Bring in external help from friends, families or professionals so you can take a break or get help with care tasks you are uncomfortable doing.

Ask for help

Get help early, not when you are stuck in an emergency situation. Look into options for respite, counselling or other sources of activity and support early on. When people offer help, accept the offer and suggest specific tasks (i.e., housekeeping, transportation, meals). Support groups can be a great source of connection, respite and resources, especially ones for caregivers-only.

Avoid multi-tasking

When we think we are "multi-tasking", we are really "switch-tasking". Our bodies and brain can only process so much, and can really only be efficient focusing on one thing at a time. Do yourself a favour and focus on one thing. Take control of technology to avoid distraction. Schedule what can be scheduled. Focus on the person you are with or task you are doing – everything else can wait!

Self-compassion

Caregivers' jobs are one of the hardest; so be kind to yourself. Talk to yourself like you would talk to a best friend. Extend support, be non-judgmental and know that you are not alone.

(Imke et al., 2012; Zellick, 2012)



CAREGIVER SELF-ASSESSMENT

Assessing yourself allows you to help balance out your needs with those of your care recipient, and teases out the areas of greatest concern.

Rate each item below from 1 to 5 according to how much of the time each statement applies to you, with 1 being "almost always" and 5 being "never".

I exercise on a regular basis	1	2	3	4	5
I make and keep preventative and necessary medical and dental appointments	1	2	3	4	5
I have a job or regular volunteer activity that is gratifying	1	2	3	4	5
I do not use tobacco products	1	2	3	4	5
I do not use alcohol or drugs	1	2	3	4	5
I get an adequate amount of sleep each day	1	2	3	4	5
I have a hobby or recreational activity I enjoy and spend time doing	1	2	3	4	5
I eat at least three balanced meals a day	1	2	3	4	5
I have at least one person in whom I can confide (tell my problems, discuss my success)	1	2	3	4	5
I take time to do things that are important to me (e.g. church, garden, read, spend time alone)	1	2	3	4	5
I do not have a problem with sleeplessness or anxiety	1	2	3	4	5
I have personal goals and am taking steps to achieve them	1	2	3	4	5
TOTAL SUM					

To score: Add the numbers and compare to the scale below.

To interpret the score:

12–24	You are doing an excellent job taking care of yourself.
25–36	You have room for improvement. Examine the areas where you struggle, and seek help.
37–48	You are doing a poor job taking care of yourself and are at moderate risk for health problems. Ask someone to help you create and stick to a plan to take better care of yourself.
48–60	You are at extremely high risk for personal health problems. It is important for you to talk to your personal healthcare provider as soon as possible. Remember, you can only provide good care for someone else if you take good care of yourself.

(Adapted from Parkinson's Foundation, 2016)

STRESS MANAGEMENT

Learn how to recognize the signs of stress. Do you become exhausted, angry, frustrated, resentful, irritable, sad, lonely, sleep deprived, panicked, anxious, depressed, cold, develop an ulcer or have other physical, mental or emotional complaints? As caregivers, we need to learn how to cope with our stress, or we put ourselves at risk of burning out!

Breathing and relaxation techniques

The effectiveness of breathing and relaxation strategies to improve stress and mental health are well-known. Yoga-based breathing and relaxation techniques normalize the function of the autonomic nervous system (i.e., the system that largely unconsciously regulates heart rate, digestion, urination, arousal, respiratory rate, pupil response) – moving away from sympathetic activation (i.e., “fight or flight” response) and towards parasympathetic stimulation (i.e., “rest and digest” response). Breathing and relaxation techniques decrease heart rate and blood pressure, lessen stress response, decrease anxiety, improve control of thoughts, increase optimism, boost immunity, increase compassion, improve feelings of emotional, spiritual and social well-being.

Try it! Read first, then practice. Sit comfortably in a chair. Take slow, deep breaths through your nose and focus your attention on the direction of your breath moving in and out. Keep attention on your breath. While you continue to take slow, deep breaths, you may begin to become aware of your body. On your inhale, notice the air moving in filling your abdomen, expanding your rib cage and lifting your chest. On your exhale, feel the air moving out as the chest, ribs and abdomen relax.

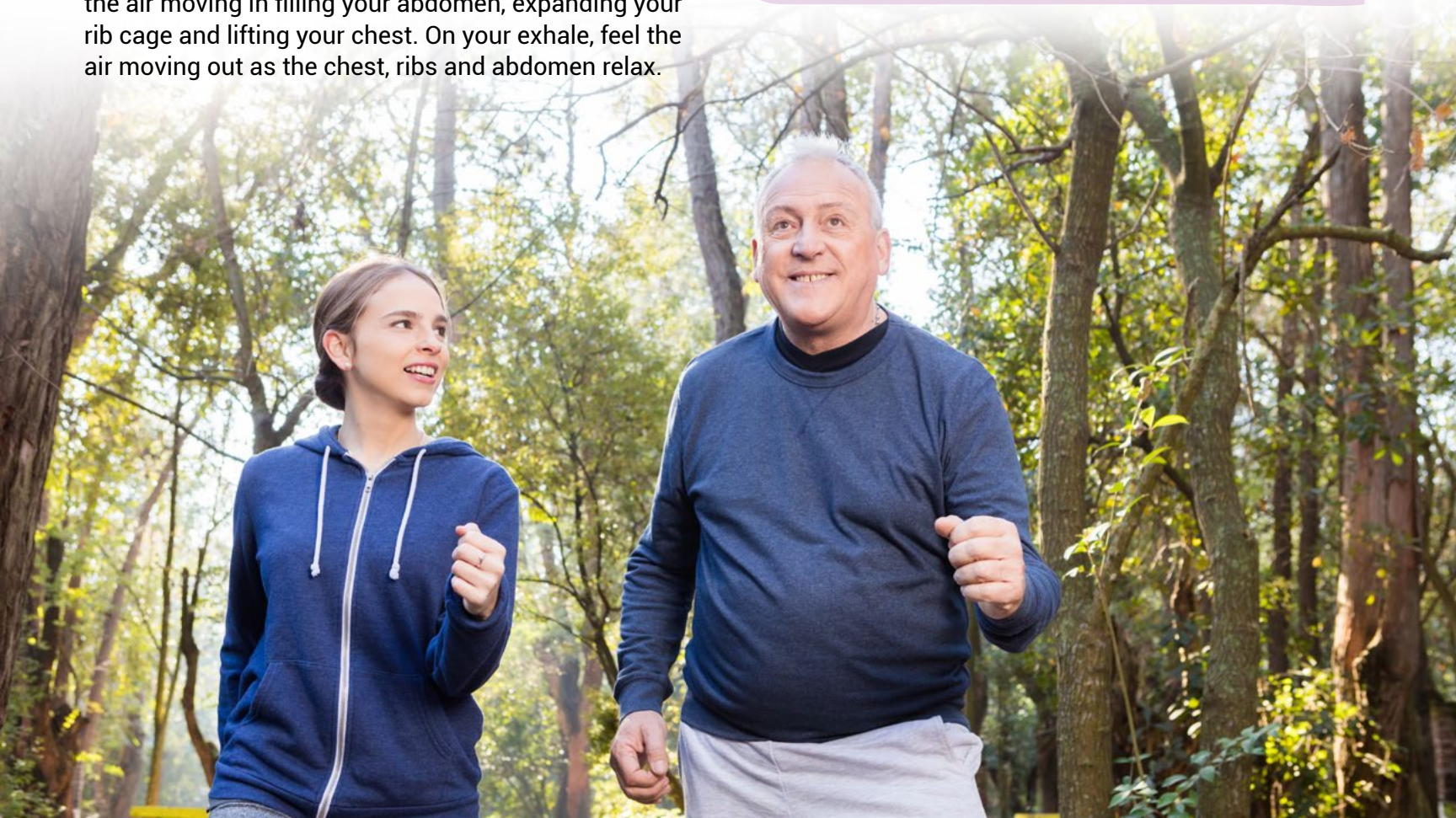
Notice any tension held in your body. Practice releasing the tension in your body by saying to yourself “Breathing in, I’m aware of my body. Breathing out, I release the tension in my body”. Imagine yourself in a safe, calm and restful place. Repeat this quick relaxation exercise a few times to reap the benefits.

Exercise

We all know exercise is good for us, but it can seem hard to fit it into your day when you are busy and stressed. A little bit of exercise can go a long way to improving your overall health and well-being. Exercise can improve focus, give you energy, improve optimism, increase self-confidence, improve relaxation, lower symptoms of depression/anxiety, decrease feelings of burden, give you a sense of control and improve symptoms of stress.

TIPS *for self-care*

- Do what you love! Any type of exercise can decrease stress; consider walking, cycling, yoga, swimming or gardening
- Start small and build up the duration and intensity as you go
- Schedule it in your calendar and make it a habit (like brushing your teeth!)
- Have goals to keep yourself motivated
- Find a friend to keep yourself committed



TIPS *for staying social*

- Have someone to talk to, in person, online or over the telephone
- Meet up with friends
- Combine exercise with socialization – go for a walk with a buddy
- Attend a support group meeting
- Have people visit you in your house
- Attend a spiritual or religious group gathering

SOCIALIZATION

Very few caregivers can care for someone day and night without any relief. The need to be “on-call” all the time can lead to distress. The ways in which we relieve stress is individual to each of us; however, we all require a certain amount of socialization. Socialization can be defined as “me time” and getting out into the world for a bit. This does not mean running necessary errands – you are still in work mode!



TIPS *for a better sleep*

- Maintain a regular sleep-wake schedule as much as possible
- Have a consistent bedtime routine
- Do breathing or relaxation techniques before sleep
- Take a few minutes every day for exercise and fresh air
- Cut down on caffeine and liquids before bed
- Nap when you can (try to limit naps to 20-30 minutes and avoid late afternoon or early evening if that impacts your ability to fall asleep at night)
- Minimize night-time noise and lights

SLEEP

Adequate sleep is essential for you to function well and be healthy. Lack of sleep can decrease your immunity and increase your risk for depression, mood changes, high blood pressure, diabetes, obesity, heart attack and stroke. Poor sleep can also decrease your ability to effectively carry out day-to-day activities or care duties.



TIPS for journaling

- Track one emotion (a sign of stress) you are most concerned with each day and note what happens when you feel this emotion. What are the triggers or patterns associated? Use that awareness to avoid triggering that feeling of stress in the future or know when you need to take a break in order to avoid becoming stressed.
- Each night before bed, write down 2 things from your day that you are grateful for. It can be something small like enjoying a sandwich at lunch or something bigger. This exercise will encourage you to focus on some positives within your day.

JOURNAL WRITING

Writing in a journal (or diary) can be quite liberating. If you haven't tried this before it may feel uncomfortable at first, but sharing your thoughts and feelings (with yourself!) can be very powerful. It takes strength to truly share our thoughts and feelings, and to do so with someone else can be unsettling at times. We may think they will judge us or feel badly for our situation. Writing in a journal bypasses these thoughts and facilitates a therapeutic release that you share with yourself.

COUNSELLING

If you don't have access to a trusted friend or companion, seek out a professional. Counselling offers a non-judgmental space where you can share what is important to you whether that is related to your loved one with Parkinson's or friends that you have had a falling out with. Counsellors offer a listening ear and a space that you can truly make your own. For more information on PSBC's counselling service, email counselling@parkinson.bc.ca or visit www.parkinson.bc.ca/counselling.

In British Columbia, the BC Association of Clinical Counsellors (BCACC) is another great resource to find a registered counsellor in your community. Find the support you need now. Use "Find a Counsellor" by calling Toll-Free 1-800-909-6303, or visit the website www.bc-counsellors.org to start working with a mental health professional today.

You may also want to find a social worker that can help you with various support services for you and your loved one. Contact your local mental health centre to start a conversation with a mental health professional by calling HealthLink BC at 8-1-1 or visiting the website at www.healthlinkbc.ca.

(Castro, Wilcox, O'Sullivan, Baumann, & King, 2002; Mayo Clinic, 2015; Canadian Virtual Hospice, 2015; Sengupta, 2012)

SUPPORT GROUPS

A support group can play an important role in your well-being. Some support groups may be targeted specifically to caregivers, while others include both partners in care. Find a support group environment that you are comfortable in. It is important to note that everyone experiences Parkinson's uniquely and a group may be diverse in the ways in which symptoms present themselves, how medication is used for management, and different care preferences.

Support groups are a means to find resources to help ease the burden of care responsibilities. Use the support group as an opportunity to ask questions, discuss concerns and experiences, and connect with others who are in a similar situation as you. Support groups may also have guest speakers to give lectures on a variety of topics related to Parkinson's disease care and management.

Support groups also act to remind you that there are others going through this with you. With support from others, you will be able to supplement your abilities in those areas in which you are less confident.

There are other resources that you can access as a carepartner that can offer support for you and your loved one. The following is a list of some of the resources that are made available to you.

BUILDING RESILIENCE

Resilient people know they have control over themselves in the present moment – they trust their own strengths, they acknowledge that there are risks and unknowns, but also know where and when to ask for help. Resilient people can be okay with uncertainty and adapt to change healthfully. Resilient people remain optimistic, persevere and savor the moment.

One of the common myths about resilience is that some people are simply born with it, while the rest of us aren't. The good news is that anyone can build the skills necessary to cope and even thrive in difficult times. The first step is recognizing that resilience is a choice. One common mistake people make when a crisis hits, or when they're dealing with a stressful situation is to think, "This is how it is, this is how it's going to be, and it's never going to get better." That's just not true. Here are some suggestions for taking steps toward creating a more resilient life.



Learn to pause

The first thing to learn is how to take a moment when you're triggered. That means being aware of what's pushing your buttons, and taking a breath or a walk. We often make the situation worse by going into rage, terror, fear, worry, or depression. If you can recognize that your thoughts and feelings have converged in a negative place, it's helpful. It's important to allow yourself to feel sad, lonely, or scared—but resilient people don't stop there. They reach out for help.

Lean on the right people—not someone who is going to make you feel worse— this is one of the healthiest ways to move forward. The skillful next step is to contact a good friend, an expert, or a life coach.

Learn your signature strengths

Resilient people lean into difficult moments from their strengths. Not sure of your strengths? You can visit www.viacharacter.org for a free inventory to determine your own 'signature strengths' (© Martin Seligman). Signature strengths can include humour, perseverance, zest, gratitude, forgiveness, leadership, and hope. These strengths can help you determine how to best approach a challenge or stressor. Is it with humour? Taking a leadership role? Or by creating a positive environment?

Learn how daily practice leads to breakthroughs

If you practice using your strengths to navigate your day, you eventually learn this crucial point: You can shape each day as an opportunity for growth. Think of each day as an experiment in which you can choose to experience happiness or misery, in which you can become your best self and make the most of it.

Learn to find the benefits

Resilient people look for the upside of a situation, even during the darkest times. Nelson Mandela famously said that his 27 years in prison afforded him two great benefits: He had time to read and time to think. In other words, as Ralph Waldo Emerson wrote, "The same world, to different minds, is a hell and a heaven." The circumstances don't matter that much. The secret to a happy, resilient life is your perspective.

As a caregiver, there are many aspects of your daily life that need your attention, both for you and your loved one. Being able to take some time for yourself and reflect on your own needs as a caregiver are equally, if not more, important than supporting someone else. Identify your needs and find your own support.

(Sirois, 2015; Kripalu Center for Yoga & Health, 2017)

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APPENDIX: INFORMATION FOR CARE PLANNING

Contact and Medical Information

List emergency information including:

☐ Address: _____

☐ Contact number: _____

☐ Date of birth: _____

☐ Insurance information: _____

☐ Doctor contact: _____

☐ Hospital contact: _____

☐ Drugstore contact: _____

☐ Caregiver contact: _____

☐ Alternative caregiver: _____

☐ Other assistance (transportation, meals, church, medical equipment, security): _____

What is the diagnosis? Are there more than one?

Diagnosis: _____

Diagnosis: _____

Diagnosis: _____

A comprehensive list of medication, detailed timing (days of week, number of times per day, time of day), and how they should be given (with/without food, water). Consider making a weekly schedule spreadsheet and include any warnings (i.e., may cause dizziness or headache, do not take with alcohol).

For example:

Med	Use	Dose	Notes	Mon am/pm	Tue am/pm	Wed am/pm	Thu am/pm	Fri am/pm	Sat am/pm	Sun am/pm
EXAMPLE										
Sinemet CR 50/200	PD	1 pill	Empty stomach with water and crackers	8 / 3	8 / 3	8 / 3	8 / 3	8 / 3	8 / 3	8 / 3
MiraLAX®	Constipation	17g	N/A	8 / 3	8 / 3	8 / 3	8 / 3	8 / 3	8 / 3	8 / 3

Information on any Functional Limitations and Special Equipment Requirements

What are the functional limitations of the person – what can/cannot he/she do for daily activities and keep track if this changes. Such as:

- ☐ Bathing: _____
- ☐ Dressing: _____
- ☐ Shopping: _____
- ☐ Eating: _____
- ☐ Mood: _____
- ☐ Mobility: _____
- ☐ Toileting: _____
- ☐ _____
- ☐ _____

What equipment is needed? Are there any special precautions? Supplies?

For example:

- ☐ Glasses: _____
- ☐ Hearing aids: _____
- ☐ Mobility aids: _____
- ☐ Bedside commode: _____
- ☐ Grab bars: _____
- ☐ Oxygen: _____
- ☐ Catheter: _____
- ☐ Incontinence pads: _____
- ☐ Transportation: _____
- ☐ _____
- ☐ _____

Nutritional Considerations

What are nutritional requirements? Is there any special diet to consider? Supplements?

- ☐ Low protein with medication: _____
- ☐ Lactose intolerant: _____
- ☐ Gluten free: _____
- ☐ Diet considerations: _____
- ☐ Diet considerations: _____
- ☐ Melatonin at bedtime: _____
- ☐ Vitamin D supplement: _____
- ☐ _____
- ☐ _____

Daily Routine Schedule

What activities does the person with Parkinson's enjoy? Consider planning an activity schedule for the day including timing and types of activities: exercise, medication, meals, naps, bedtime routine toileting/bathing, dressing, television, activities and errands.

Health Service Resource Use

What are services the home healthcare agency provides? Do you need additional services? Where can or do you get these?

Type of Service	Provided By... (company name / contact)	When and Where	Other Details
EXAMPLE			
Housecleaning	Holly's housekeeping 250-XXX-XXXX	Our home Tuesdays 3 - 4pm	Put cat in bedroom before she arrives
Your Health Service Resources			

(Adapted from Meyer et al., 2007)

NOTES

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

NOTES

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

NOTES

This image shows a full page of white paper with horizontal blue or grey ruling lines. The lines are evenly spaced and run across the width of the page, typical of notebook paper. There are no margins, text, or other markings on the page.



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