EMPOWERING YOURSELF IN HEALTHCARE

A GUIDE FOR INDIVIDUALS LIVING WITH PARKINSON'S

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INTRODUCTION – EMPOWERING YOURSELF IN HEALTHCARE

A Parkinson's diagnosis brings a mix of emotions—uncertainty, fear, and even frustration—as you adjust to a new reality. It's important to acknowledge that these feelings are both natural and valid, and that you are not alone— many others have faced similar reactions after their diagnosis. Many individuals find themselves in a difficult space immediately following their diagnosis, sometimes feeling left out in the cold while waiting for their next appointment, which may be as far as a year away. This gap in care can leave you feeling lost, unsure of what steps to take, and struggling to process the changes ahead. However, while this transition can feel daunting or overwhelming, rest assured that support and resources are available to guide you through your care. Taking charge of your healthcare is a powerful way to regain a sense of control, build confidence, and continue living a purposeful life, engaging in the activities that matter most to you.

A common question individuals may have is, "Where do I go from here?". Parkinson Society Southwestern Ontario (PSSO) is committed to providing a compassionate and empowering community for those living with Parkinson's. With a dedicated team of knowledgeable and compassionate staff, PSSO offers the resources, care, and support needed to make a real difference.

Understanding the power of connection, PSSO integrates this core value into all its initiatives and strives to walk alongside individuals, offering the guidance and encouragement they deserve. Get connected today! The *Code* applies to public and private organizations in Ontario but does not apply to the federal government or federally regulated organizations, which are instead governed by the *Canadian Human Rights Act.*

Empowering yourself in healthcare means taking an active role in your care and advocating for yourself to ensure your rights and needs are recognized. This involves understanding your legal rights within the healthcare system—such as access to publicly funded healthcare, the right to seek a second opinion, and more—knowing how to assert these rights, whether through self-advocacy or issuing a formal complaint, and knowing how to advocate for yourself in a way that communicates your needs effectively, ensuring you receive quality care. This might also include adopting practical strategies to engage more fully in your care, such as keeping a symptom journal to track changes over time, preparing questions for your doctor prior to your appointments, and familiarizing yourself with available resources. Equally important is recognizing that you don't have to go through this journey alone. Whether through formal support groups or informal connections, connecting with others navigating Parkinson’s, can provide a sense of shared experience, offering valuable emotional support and practical insights as you move forward with your care.

This document is designed to help you navigate the healthcare system by:

- Understanding your legal rights and how to assert them;
- Adopting practical strategies to take an active role in managing your care;
- Getting connected with the support systems and resources available to you and your loved ones.

By becoming informed and proactive, you can ensure that your voice is heard, and take steps to manage your health in a way that works best for you.

KNOWING YOUR RIGHTS

1. Healthcare Standards in Ontario

There is legislation in Ontario which governs the standard of care that must be met by healthcare organizations when providing treatment for Parkinson’s Disease and healthcare services in general.

Excellent Care for All Act

The *Excellent Care for All Act*[1] establishes standards that all publicly funded healthcare organizations must follow. It aims to ensure that all Ontarians receive high-quality health care. The Act governs issues related to quality of care, complaints, and enforces accountability. Importantly, the Act also sets out the role of the patient ombudsman of an organization who you can submit a complaint to about your health care experience.

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[1] *Excellent Care for All Act*, 2010, S.O. 2010, c. 14.

Section 13.2: A patient, former patient, or caregiver is entitled to make a written complaint to the patient ombudsman of an organization about the actions or inactions of a health sector organization. The patient ombudsman must work with the patient to facilitate a resolution, with some exceptions.

2. The Right to Informed Consent - *The Health Care Consent Act (HCCA)*

The *HCCA*[2] outlines rules with respect to consent to treatment. The Act notes that a physician cannot commence any non-emergency treatment without the patient's consent [section 10(1)]. Consent to treatment can be withdrawn at any time [section 14]. Should you choose to refuse or revoke consent, you must do so clearly. Ensure that the absence of consent is documented.

In order for consent to treatment to be considered informed, the patient must be made aware of all benefits and risks associated with the procedure [section 11]. The patient must also be informed of the nature of the procedure, as well as alternative treatment options should they choose to refuse or withdraw consent. Healthcare providers bear the responsibility of ensuring patients have a comprehensive understanding of their treatment. Patients are encouraged to ask questions until they feel confident in their decision to proceed.

The *HCCA* also aims to facilitate treatment, admission to care facilities, and personal assistance services, for persons lacking the capacity to make decisions about such matters.

Substitute Decision Makers and Consent

If it is found that due to the impact of your Parkinson's symptoms, you may have difficulty providing consent, a substitute decision maker may be able to give consent to treatment on your behalf under **section 10(b)** of the *HCCA*.

Power of Attorney

To ensure your wishes with respect to treatment are followed, you may consider setting up a power of attorney in advance to make decisions on your behalf in the future. The *Substitute Decisions Act*[3] provides some guidance about when you can use a power of attorney and their role.

Section 46 of the Act discusses power of attorneys for personal care. You can give a written power of attorney for personal care, authorizing the person or persons named as attorneys to make decisions concerning your personal care on your behalf **(section 46(1))**.

To set up your power of attorney, you don't need to use a special form. However, for the document to be valid, it must include:

- The name(s) of the persons you would like to act as your power of attorney for your personal care
- Your signature, which must be dated
- The signatures of two witnesses

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[2] *Health Care Consent Act*, 1996, S.O. 1996, c. 2, Sched. A.
[3] *Substitute Decisions Act*, 1992, S.O. 1992, c. 30.

Your power of attorney must do their best to follow your wishes, both written and unwritten, when making decisions on your behalf.

For more information about powers of attorney, see: https://www.publications.gov.on.ca/300629

Decision Making Without a Power of Attorney

If you choose not to set up a power of attorney, the *HCCA* outlines other people who may become substitute decision makers on your behalf.

Section 20(1) provides a list of people who may give or refuse consent on your behalf:

1. Guardian
2. Power of attorney for personal care (*see section above: power of attorney*)
3. Representative appointed by the Consent and Capacity Board
4. Spouse or partner
5. Child
6. Parent
7. Brother or sister
8. Any other relative

3. Right to Request Access to Medical Records - *Personal Health Information Protection Act* (PHIPA)

Under the Personal Health Information Protection Act (PHIPA), you have the right to request access to your medical records and make corrections to them.[4] You may need to do this when requesting referrals, when seeking out a second opinion, and when insurance companies ask for documentation of your diagnosis and treatment plan. You may also want to access your medical records simply to be more informed about your medical history and to better understand your health conditions, in turn allowing you to participate more actively in your healthcare decisions.

To access your health records you must first identify what exact medical information you're looking for. Then you need to contact the custodian of the medical records in question, such as a doctor, hospital, or clinic, and request access from them. This custodian may ask you to compose a formal request in writing, for which you may either fill out a Request to Access Personal Health Information Form or write a letter of your own. A substitute decision-maker (see page 4 for more information about substitute decision makers) can also make this request on behalf of the patient. The custodian must decide whether to grant access and respond to the request within 30-60 days.[5]

The custodian may charge a fee to access or transfer the requested medical records. If they do charge a fee, they must provide the patient with an estimate of the fee amount beforehand, and the fee amount must not exceed what the custodian reasonably needs to cover the cost of providing access. Fee guidelines published by the Information and Privacy Commissioner of Ontario (IPC) determine what is "reasonable".

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[4] *Personal Health Information Protection Act*, 2004, S.O. 2004, c. 3, s. A, 1.
[5] Information and Privacy Commissioner of Ontario, "Accessing or correcting your personal health information", online, https://www.ipc.on.ca/en/health-individuals/accessing-or-correcting-your-personal-health-information

The right to access medical records is not absolute, and there are certain situations that the IPC lists as examples of scenarios in which a custodian may legally deny your request. These include situations where[6]:

- the health records in question are subject to a legal privilege such as solicitor-client confidentiality
- access to the medical records may cause a risk of serious harm to the patient or somebody else
- the health records are part of an investigation, inspection, or similar procedure that has not yet finished
- another law prohibits disclosing the requested health records

Furthermore, the right of access does not include some medical information, such as raw data from standardized psychological tests.

A patient, or their substitute decision-maker, can request a correction to their medical records if they have been provided access to the records and they believe that the information contained in them is incomplete or inaccurate. The custodian of your health records must correct the records if you can prove that your records are inaccurate or incomplete and you provide the correct information. The custodian may ask you to compose a formal request in writing for the correction, for which you may either fill out a Request to Correct Personal Health Information Form or write a letter of your own. A substitute decision-maker can also make this request on behalf of the patient. The custodian must decide whether to accept the correction and respond to the request within 30-60 days.[7]

However, the IPC provides examples of situations in which a custodian may legally deny your correction request[8]:

- they are not convinced that the record is inaccurate or incomplete for the purposes they use the medical information for
- they are not convinced that you have supplied the information that they need to make the correction
- the record that you're requesting to be corrected was not originally created by them and they lack sufficient authority, knowledge, or expertise to make the correction
- the record includes professional observations or opinions that were made in good faith

If the custodian denies your formal access or correction request, they must provide you with an explanation for why they did so.[9]

A patient or substitute decision-maker can file a complaint with the IPC if they feel that their access request or correction request has been wrongly denied. They may do this by completing the Access/Correction Complaint Form on the IPC website.

4. Right to Seek Second Opinion

The Canadian Medical Association's *Code of Ethics and Professionalism* states that a patient has the right to seek out a second opinion about a diagnosis or treatment plan, at any point in the diagnosis or treatment process.[10] To do this, you can ask your doctor's office for a referral to a different doctor or specialist. If you wish, this can be to a doctor or specialist of your own choosing. Alternatively, you can also check independently with another clinic or hospital to receive a second opinion.

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[6] "Accessing or correcting your personal health information" (footnote 5).

[7] "Accessing or correcting your personal health information" (footnote 5).

[8] "Accessing or correcting your personal health information" (footnote 5).

[9] "Accessing or correcting your personal health information" (footnote 5).

[10] *Code of Ethics and Professionalism*, Canadian Medical Association (2018), p.5.

When you book the appointment with the second doctor, you should tell them that you are looking for a second opinion, and have your first doctor's office send any health records relevant to your diagnosis and/or treatment plan to the second doctor's office. Your doctor is obligated to provide the information that is needed to facilitate the referral for a second opinion, and cannot make you face any negative consequences for seeking one. Alternatively, if you prefer you can request access to the relevant medical documentation from your first doctor's office and send it to the second doctor's office yourself.

The Canadian Medical Protective Association states that if the second doctor recommends a treatment plan different from that recommended by your first doctor, your first doctor is under no obligation to carry out the second doctor's treatment plan if they disagree with it.[11] However, the second doctor could carry out that treatment plan with you independently.

In Ontario second opinions are covered under the provincial healthcare plan as long as they are referred by a doctor or specialist.

5. Demanding Referrals

The CPSO (College of Physicians and Surgeons of Ontario) states that, when making decisions relating to formal clinical referrals and effective referrals, physicians in Ontario are prohibited from discriminating against patients based on grounds protected under the Human Rights Code, including on grounds of disability or health condition.[12] In other words, referring physicians are legally obligated to ensure that their patient is referred to a non-objecting, accessible, and available physician, other health-care professional, or agency, regardless of any medical condition(s) the patient may have.

The referring doctor must make the referral in good faith, and the referral must be timely in order to allow patients to access care and not be exposed to negative clinical outcomes as a result of a delay.

When physicians provide formal clinical referrals, they have an obligation to comply with the expectations listed in the *Transitions in Care* policy. *Transitions in Care* is a policy of the CPSO (College of Physicians and Surgeons of Ontario), which means that if a physician fails to comply with it, a patient or substitute decision-maker has valid grounds to make a complaint against the physician with the CPSO. *Transitions in Care* protects patients in the following ways regarding referrals[13]:

- Referring physicians must clearly convey to patients what their role will be in the patient's treatment program during the referral process. Consultant physicians (the ones receiving the referrals) must also clearly discuss with patients the nature of their role, such as what elements of care they will be responsible for.
- When transferring primary responsibility for patients to a different health-care provider, physicians must provide for an up to date and comprehensive exchange of information with the new physician the patient is being referred to.

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[11] Canadian Medical Protective Association, "When a patient seeks a second opinion" (September 2023), online, https://www.cmpa-acpm.ca/en/advice-publications/browse-articles/2014/when-a-patient-seeks-a-second-opinion#:~:text=Patients%20have%20the%20right%20to%20make%20decisions%20about%20their%20health,assessment%2C%20there%20is%20no%20conflict.

[12] College of Physicians and Surgeons of Ontario, "Human Rights in the Provision of Health Services" (September 2023), online, https://www.cpso.on.ca/en/Physicians/Policies-Guidance/Policies/Human-Rights-in-the-Provision-of-Health-Services.

[13] College of Physicians and Surgeons of Ontario, "Transitions in Care" (September 2019), online, https://www.cpso.on.ca/Physicians/Policies-Guidance/Policies/Transitions-in-Care.

- Consultant physicians are obligated to acknowledge referrals in a timely manner, no later than 14 days from the day the referral is received. When acknowledging the referral, consultant physicians must communicate to the referring health-care provider whether or not they can accept the referral.
- Consultant physicians must convey the expected wait time or the appointment date to the patient, unless the referring physician has stated that they will do so
- Physicians using technology to prepare and distribute referral requests must make sure that they are accurate and follow-up with the receiving healthcare provider if they identify any errors after the referral has been sent

6. Patient Acceptance and Termination of Care

Healthcare providers must follow CPSO guidelines when accepting or ending patient relationships.[14] If you feel that these guidelines have not been followed in your own healthcare experiences, please see the passage below on submitting formal complaints to the CPSO.

6.1 Accepting New Patients:

- Physicians and specialists must admit new patients on a first-come, first-served basis, except when urgent medical needs dictate otherwise.[15] They cannot discriminate against patients with complex or chronic conditions.[16] If care cannot be provided, patients must be informed promptly, with a clear explanation.[17]

6.2 Ending Patient Relationships:

- When discontinuing care, a physician must provide formal notice, allowing adequate time for the patient to secure alternative care. They are also required to assist in the transition process, particularly for patients with disabilities or special needs. During the transition, the physician must continue to provide necessary services, including prescription renewals and follow-up on existing tests.[18]

7. Wait Times and Delays

The *Canada Health Act* emphasizes the importance of reasonable access to healthcare; however, it does not guarantee a legal right to timely care or appropriate wait times.[19] Nonetheless, patients can take proactive steps to advocate for more timely treatment:

1. **Inquire About Cancellation Lists -** Ask your healthcare provider if they maintain a cancellation list. Being available on short notice may allow you to secure an earlier appointment.

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[14] College of Physicians and Surgeons of Ontario, "Advice to the Profession: Accepting New Patients" (May 2019) online, https://www.cpso.on.ca/en/Physicians/Policies-Guidance/Policies/Accepting-New-Patients/Advice-to-the-Profession-Accepting-New-Patients

[15] College of Physicians and Surgeons of Ontario, "Accepting New Patients" (May 2017) at paras 1, 8, 13, online, https://www.cpso.on.ca/en/Physicians/Policies-Guidance/Policies/Accepting-New-Patients#:~:text=First%2DCome%2C%20First%2DServed,practice%20area%201%20%3B%20and%2For

[16] "Accepting New Patients" at para 4(a) (footnote 15).

[17] "Accepting New Patients" at para 5(c) (footnote 15).

[18] College of Physicians and Surgeons of Ontario, "Ending the Physician-Patient Relationship" (May 2017) at paras 16-20, online, https://www.cpso.on.ca/Physicians/Policies-Guidance/Policies/Ending-the-Physician-Patient-Relationship

[19] *Canada Health Act*, 1985 R.S.C. 1985, c.6, s.3.

2. **Join Multiple Waitlists -** The College of Physicians and Surgeons of Ontario mandates that patient intake operates on a first-come, first-served basis, except in cases of urgent medical need.[20] Joining multiple waitlists for specialists or primary care providers can improve your chances of securing timely care. Remember to remove yourself from any remaining lists once you've received care to avoid unnecessary delays for others.

3. **Discuss Wait Times With Your Provider -** The wait times for certain types of treatment may be determined based on your doctor's assessment of how urgently you need medical care. Do not hesitate to question your doctor on how your priority level was determined and to correct any misconceptions they may have about your level of urgency. It may also be beneficial to inquire about the clinically appropriate timeframe within which the treatment or procedure needs to be performed.

4. **The Role of Caregiver and Social Workers -** For patients who struggle with self-advocacy, caregivers and social workers may need to step in to ensure that medical care is received in a timely manner. Depending on the individual, caregivers and social workers may need to initiate conversations with doctors. However, there are many ways to support patients while still encouraging them to advocate for themselves. Keeping detailed notes on the patient's symptoms and needs can give the patient a solid foundation to present to their healthcare provider when trying to advocate for earlier appointments. It may also be helpful to attend appointments, where appropriate, to offer moral support to patients while still allowing them to speak for themselves. Further support that can be provided in the interim may include helping with any anxiety or mental health issues related to long wait times. It can be quite frustrating and disheartening to feel unseen by your healthcare provider. Good ways to help the individual remain optimistic include helping the patient stay active, facilitating social interactions, and finding outlets like hobbies and community events. See pages 13-15 for a list of engagement resources that may be a good fit! Another struggle that patients experience is feeling like they have lost control over their life – get creative in finding everyday accommodations to help patients carry out everyday tasks on their own! For example, for individuals struggling with tremors, the kitchen can be made more accessible by adding tools such as weighted utensils, kettle tippers, reusable straws, and finding items like plates and cutting boards with raised edges.

8. Financial Rights and Supports

8.1 Understanding Publicly Funded Healthcare in Ontario

In Canada, publicly funded healthcare is often known as "Medicare". This system is designed to ensure that all residents have access to medically necessary healthcare services without financial or other barriers. The *Canada Health Act*[21] sets the foundation for this system, requiring provinces and territories to provide healthcare services which are universal, publicly funded and accessible.

Each province manages its own healthcare system. In Ontario, this is done through the Ontario Health Insurance Plan (OHIP).

Your Rights Under Ontario's Healthcare System:

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[20] "Accepting New Patients" at paras 1, 8 (footnote 15).

[21] *Canada Health Act*, R.S.C., 1985, c. C-6.

The *Commitment to the Future of Medicare Act, 2004* [22]protects publicly funded healthcare in Ontario. Under this law, you cannot be charged any extra fees for healthcare services which are covered through OHIP. Additionally, you have equal access to medical care, meaning that your financial situation cannot hinder your ability to receive treatment. This means that if you require care for Parkinson's disease, you cannot be denied medically necessary services because of cost.

OHIP Coverage for Parkinson's Care

OHIP covers many essential healthcare services for Parkinson's patients, including:

- Visits to your family doctor and most neurologist appointments
    - If you require a visit to the neurologist or movement disorder specialist, your family doctor can provide a referral. OHIP covers most visits to specialists when referred by a physician.
- Diagnostic tests such as CT scans and MRIs (when deemed medically necessary)
- Hospital stays and emergency care
    - Some home care and long-term care services

OHIP will NOT cover:

- Prescription medications
    - **However:**
    - OHIP+ covers prescription medications for children and individuals under 25 without a private drug plan
    - Ontario Drug Benefit plan pays for some prescriptions for people over 65, who get social assistance, and long-term care patients
    - Ontario's Trillium Drug Program helps pay prescription costs for individuals with significant drug costs compared to their family income
- Physiotherapy, occupational therapy, and speech therapy (unless received in a hospital or through government-funded programs)

How to Advocate for Your Health Coverage

- If you believe you are being charged incorrectly for OHIP-covered services or are being denied necessary care, you can: contact the Ontario Ministry of Health to report extra billing or being denied access to covered services.

For more information see:

- Ontario Health Insurance Plan (OHIP)
- Ontario Ministry of Health: contact the Service Support Contact Centre by calling 1-800-262-6524

8.2 Financial Support and Benefit Programs in Canada

Disability Tax Credit

People with Parkinson's may qualify for the Disability Tax Credit (DTC), a non-refundable tax credit that helps reduce the amount of income tax owed. This credit is designed to offset some of the extra costs associated with disabilities.

How the DTC can help:

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[22] *Commitment to the Future of Medicare Act*, 2004, S.O. 2004, c. 5.

- Reduces the income tax you or a supporting family member have to pay
- Recognizes the financial burden of living with a disability
- May provide retroactive tax relief for up to 10 years if approved

How to Apply:

- Visit the Canadian Revenue Agency website: Disability Tax Credit

Canadian Pension Plan Disability Benefits

Individuals with Parkinson's may also be eligible for the Canadian Pension Plan (CPP) Disability Benefits, which provide monthly financial support to those who have made enough contributions to the CPP and are unable to work due to a severe and prolonged disability.

Eligibility:

To qualify for CPP benefits you must:

- Have a severe and prolonged disability which prevents you from working regularly
  - Severe: Disability prevents you from working regularly at any job
- Have contributed to the CPP for a minimum number of years
  - You must have contributed to the CPP in 4 of the last 6 years
  - If you have contributed for at least 25 years, you only need contributions in 3 of the last 6 years
- Be under the age of 65 (those 65 and older may qualify for CPP retirement benefits instead)

How Much You Could Receive:

- The basic payment amount is $598.49, with additional amounts based on past CPP contributions
- The maximum monthly CPP disability benefit in 2025 is $1,673.24
- If you are receiving disability income from other sources, such as a private insurer or a provincial program, you may still be able to receive the CPP disability benefit
  - However, these other sources may change their payments if you are approved for the disability benefit through the CPP
- CPP children's benefit: Dependent children of recipients may receive $301.77 per month

How to Apply:

1. Gather necessary documents: This includes a Medical Report completed by your doctor and a CPP Disability Benefit Application Form.
2. Complete the application: You can apply online or submit a paper application by mail.
3. Submit your application: Applications are reviewed by Service Canada, and you may be asked for additional medical information.
4. Receive a decision: If approved, you will receive monthly disability benefits. If denied, you can appeal the decision through the Social Security Tribunal (SST). (For more information click here).

For more details and to apply, visit: Canadian Pension Plan Disability Benefits

Assistive Devices Program

The Assistive Devices Program (ADP) helps individuals in Ontario with the cost of purchasing a variety of medical devices and equipment, which can be critical for those living with Parkinson's disease. The ADP provides financial assistance to eligible individuals to improve their quality of life by helping them acquire devices like wheelchairs, mobility aids, and other assistive technology that may be needed as part of their healthcare plan.

What ADP Covers:

The program covers a wide range of assistive devices and equipment, including, but not limited to:

- Wheelchairs (manual and powered)
- Walking aids (canes, crutches, walkers)
- Hospital beds
- Lifts and transfer aids
- Speech-generating devices
- Hearing aids and listening devices
- Orthotics, prosthetics, and other medical equipment

Eligibility:

To qualify for funding through the ADP, applicants must meet the following criteria:

- Be an Ontario resident with a valid Ontario Health Card
- Have a long-term physical disability (such as Parkinson’s disease) that is expected to last for at least 6 months
- Require the device for long-term use (at least 6 months)

How to Apply:

1. First, you need a prescription for the assistive device from your healthcare provider.
2. You must purchase the device through a vendor or supplier that is authorized by the ADP. (See ADP website linked below, to find a vendor).
3. Your healthcare provider will be able to assist in submitting an application to the ADP for approval.
4. Once the application is approved, you can purchase the device through the authorized vendor, and the ADP will cover a portion of the cost.

How Much is Covered:

While the ADP covers a significant portion of the cost of many devices, there is often a client contribution required, depending on the device and individual circumstances.

- 75% of the cost for most equipment and supplies is covered. For these items, ADP is billed directly by the supplier and you pay 25% when you buy the item.
- ADP typically supports the replacement of assistive devices every 5 years, depending on the type of device and its condition.
- The ADP does not cover the cost of repairs or maintenance for assistive devices. However, some private insurance plans may provide coverage for repairs.

More Information:

For more details, eligibility information, or assistance with your application, you can visit the official Assistive Devices Program webpage: Assistive Devices Program

Additionally, you can contact the ADP directly at:

- Ontario Ministry of Health: 1-800-268-6021 (Toll-Free)
- Email: assistive.devices@ontario.ca

Ontario Disability Support Program - Applying for Disability in Ontario:

Individuals with Parkinson's who experience financial hardship due to their disability may be eligible for support through the Ontario Disability Support Program (ODSP). ODSP provides financial assistance and employment support to eligible individuals with disabilities.

Eligibility:

To qualify for ODSP you must:

- Be at least 18 years old
- Be an Ontario resident
- Have a substantial physical or mental impairment that is expected to last one year or more and limits your ability to work, care for yourself, or function in the community
- Meet financial eligibility criteria, which consider income and assets

How to Apply:

1. Start the application: You can apply online, by phone (by calling the Social Assistance Support Line Toll-free: 1-888-999-1142 or Toll-free TTY: 1-800-387-5559), or in person at your local ODSP office.
2. Provide financial information: You will need to submit documents verifying your income, assets, and housing costs.
3. Complete the Disability Determination Package: This includes medical forms that must be filled out by a healthcare provider.
4. Receive a decision: If approved, you will receive monthly income support and may also qualify for additional benefits, such as health benefits and employment support.

  - Information regarding the income support available to you from ODSP.

5. Appeal if necessary: If your application is denied, you have the right to request and internal review appeal the decision through the Social Benefits Tribunal. (For more information click here).

For more details and to apply, visit: Ontario Disability Support Program.

9. Right to Government-Funded Care Homes

Patients with high care needs can choose to live in long-term care homes, if they meet the following criteria set by Ontario Health at Home (the organization in charge of long-term care applications)[23]:

- 18 years of age or older;
- have a valid Ontario Health Card;
- have health care needs that cannot be met with any combination of caregiving in the home or community; and
- have health care needs that can be met in a long-term care home.

During the long-term care home placement process the care coordinator ensures that there's an accurate record of your medical history and helps determine your eligibility for long-term care.

Once you are determined to be eligible, your care coordinator will discuss all options and provide a list of long-term care homes to choose from. Ontario Health atHome's website states that you can apply to a maximum of five homes, however, this maximum does not apply to patients who are assessed as experiencing a crisis in their condition or circumstances. Wait times for entry into long-term care homes can vary widely, and the care coordinator will work with you to select the right long-term care home based on this and other factors.

The Ontario Government's Ministry of Long-Term Care requires that all long-term care home residents contribute towards the cost of accommodation and meals. This is what is referred to as a co-payment fee.[24]

The amount of your co-payment fee depends on whether you are in a private, semi-private or basic room.

The Ontario Government website states that if you do not have sufficient income to pay for the basic room co-payment, the Government of Ontario can help you by providing a subsidy. This is known as the Long-Term Care Rate Reduction Program, which helps to cover the co-payment fee for eligible residents living in a basic room, and for spouses or partners of residents who live together in a semi-private room with two beds that has been reclassified as basic accommodation. There are multiple

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[23] Ontario Health at Home, "Eligibility and Admission", online, https://ontariohealthathome.ca/long-term-care/eligibility-and-admission/

[24] Ministry of Long-Term Care, "Paying for long-term care" (2 July 2024), online, https://www.ontario.ca/page/paying-long-term-care\

factors that the Ontario Government assesses to determine whether you qualify for the Long-Term Care Rate Reduction Program, including your income level and whether you need to support any dependents.[25]

If found eligible for placement in a long-term care home, you cannot be refused because of an inability to pay for accommodation and food.

The Ontario Government website makes it clear that all long-term care residents have the right to the same level of care, no matter what room type they are in. This ideal is also reflected in the Fixing Long-Term Care Act, 2021.[26]

Once in a long-term care home, residents' rights in the homes are governed by this same Fixing Long-Term Care Act, 2021, which contains a *Residents' Bill of Rights.*

The *Residents' Bill of Rights* lists 29 protected rights, and these are divided into 5 sections[27]:

Section 1: Right to be treated with respect: The right to be treated with politeness, to not be discriminated against based on protected grounds, for staff to respect your lifestyle choices, and to be involved in decision-making about life at the home.

Section 2: Right to freedom from abuse and neglect: The right to not be abused physically, sexually, financially, emotionally, or verbally, and to not be neglected by care home staff.

Section 3: Right to an optimal quality of life: The right to talk with people in private, to make friends, to share a room, to be alone with a partner or person you want to be intimate with, to pursue interests inside or outside the home, to have a safe and clean living space, to go outside, to keep personal possessions in your room, to manage our finances, and to exercise your democratic rights and equality rights as a citizen.

Section 4: Right to quality care and self-determination: The right to receive the care and services that you need, to know your caregivers, to privacy when talking about medical treatment or personal care, to be involved in your plan of care, to be consent to and be consulted about treatment, to take part in decisions about moving into or leaving a long-term care home, to be involved in decisions about moving to a different room, for your medical records to be kept confidential and private, to receive extra support and care from caregivers of your choice, to bring people to meetings, to choose your designated contact person, to receive care and assistance that maximizes independence to the greatest extent possible, to be free of restraints with a few exceptions, to get care and services that allow you to live the fullest life possible, and to have family and friends with you during critical illness.

Section 5: Right to be informed, participate, and make a complaint: The right to be told in writing about the rules you're supposed to follow and about how to file a complaint about any problems in the home, to participate in the Residents' Council, and to raise concerns and make complaints.

ASSERTING YOUR RIGHTS

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[25] "Paying for long-term care" (footnote 24).
[26] *Fixing Long-Term Care Act*, 2021 S.O. 2021, c. 39 s.1, Preamble, 3(1).
[27] *Fixing Long-Term Care Act* (footnote 26), 3(1).

1. Self-Advocating for Your Rights

By understanding your rights and the protocols governing healthcare in Ontario, you can advocate for yourself and ensure that you receive the quality of care you deserve. Do NOT be afraid to assert your rights by reminding medical professionals of the duties and obligations they owe to you as a patient.

Bringing supporting documentation—such as the relevant legislation, CPSO policy or whatever it may be—can strengthen your position and help you to feel more confident in initiating these conversations. Physicians are well aware of their professional obligations and, when reminded, should ideally adjust their approach to align with their duties. If, despite these efforts, your concerns are not addressed, you may need to take a more formal approach, such as filing a complaint. However, in many cases, a firm yet respectful reminder is enough to prompt the appropriate action and ensure you receive the care you are entitled to.

2. Filing Complaints Against a Healthcare Provider

2.1 When to File a Complaint

If you have concerns about the quality of the treatment you have received, the competence of your healthcare provider, or an issue with office administration, you can file a formal complaint. This may include difficulty with or an inability to book appointments, poor communication and delayed response times, unprofessional behaviour, unreasonable wait times, or rushed appointments.

The complaint investigation process can be lengthy. One option to circumvent this is to pursue alternative dispute resolution. Once you have filed your complaint, a mediator will inform you if you are eligible for dispute resolution. If you choose this route, you will be able to schedule collaborative meetings between your mediator and the provider in question.[28]

The CPSO also has a Patient & Public Health Centre that you can speak to directly before filing your complaint. You can contact the Help Centre by calling 416-967-2603 or toll-free at 1-800-268-7096, ext. 603. Advisors are available Monday to Friday, 8 a.m. to 5 p.m.[29]

2.2 How to File a Complaint

The conduct of nurses and doctors is overseen by governing bodies known as colleges. For physicians and surgeons, complaints should be directed to the College of Physicians and Surgeons of Ontario (CPSO). For nurses, complaints are submitted to the College of Nurses of Ontario (CNO). To file a complaint, you must

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[28] College of Physicians and Surgeons of Ontario, “Alternative Dispute Resolution (ADR)” (2025), online, https://www.cpso.on.ca/en/Public/Services/Complaints-and-Concerns/Alternative-Dispute-Resolution

[29] College of Physicians and Surgeons of Ontario, “Patient & Public Help Centre” (2025), online, https://www.cpso.on.ca/en/Public/Services/Patient-Help-Centre

be able to provide the full name of the nurse or doctor in question, the date of the incident, the name of the healthcare facility, and a detailed description of the problematic events that occurred.

A complaint about a nurse can be filed here

A complaint about a physician or surgeon can be filed here

There is no time limit on when to submit complaints, however, the sooner you do so, the better. CPSO and CNO investigations may take over a year, so it is best to begin the process as soon as possible to ensure that the wrongful conduct is corrected quickly. It is also beneficial to file soon after the incident so that your recollection of the events and relevant parties is more accurate. Further, while there is no limit on when you can submit complaints, there is a two-year timeline within which you can file a civil lawsuit against a healthcare provider. CPSO and CNO complaints can yield valuable evidence that may help you in court, so it is important not to delay the onset of the investigation.[30]

2.3 Outcomes

Once the investigation has been completed, you will receive a copy of the committee's report.[31]

Unlike a lawsuit, CPSO and CNO complaints will not yield financial compensation to the patient. However, they can result in requiring the healthcare provider to undergo additional training, placing restrictions on their practice, and most importantly, forcing your healthcare provider to take accountability for their poor conduct and make corrections to their work.[32] If the college investigates your complaint and decides no repercussions are warranted, you can appeal their decision.

ADOPTING PRACTICAL STRATEGIES TO TAKE AN ACTIVE ROLE IN MANAGING YOUR CARE

1. Understand Your Medications

Having an understanding of the purpose, dosage, and potential side effects of your medications can play a key role in managing Parkinson's effectively. Factors such as timing, whether to take medications with food, and potential side effects can all influence how well medication works for you. Following these guidelines ensures you are experiencing the intended effects of your treatment, helping your

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[30] College of Physicians and Surgeons of Ontario, "Complaints and Concerns" (2025), online, https://www.cpso.on.ca/en/Public/Services/Complaints-and-Concerns#What-happens-with-my-complaint-

[31] "Complaints and Concerns" (footnote 30).

[32] "Complaints and Concerns" (footnote 30).

healthcare provider assess your response and make any necessary adjustments to keep your treatment plan optimal for you.

Keep in mind that everyone's care plan is unique to them, and that dosages can vary from person to person. Ensure that you are taking your medication as prescribed by your doctor, rather than basing it on the amount someone else with Parkinson's is taking.

2. Keep a Symptom Journal

Tracking your symptoms daily, even the timing of your symptoms, can help identify patterns, triggers, and changes in your condition over time. This journal serves as a useful tool for discussions with your healthcare provider, ensuring they have accurate information to tailor your treatment plan. Understanding your medications and their side effects can also be helpful in keeping this symptom journal, allowing you to distinguish Parkinson's symptoms from medication side effects and recognize any severe side effects should they come up.

3. Prepare for Your Doctor's Appointments & Help your Healthcare Team Prioritize your Care

Make a plan before your doctor's appointment to ensure your top concerns and priorities are addressed during the visit. Writing out a list of questions and concerns can help keep discussions focused and maximize the limited time you have with your doctor.

While your doctor only sees you briefly, you experience Parkinson's daily and have the best understanding of how it affects you. Since Parkinson's symptoms fluctuate and progress, it's important to let your doctor know which changes are having the biggest impact on your routine, mobility, or overall well-being. Be open about the symptoms that interfere with you the most—by clearly expressing your top concerns, your team can prioritize treatments that will make the most meaningful difference in your quality of life. Preparing in advance helps you take an active role in shaping these important conversations, ensuring the most pressing issues are addressed at appointment and that your care remains tailored to your needs.

4. Ask Questions as They Come Up

Your health is personal, and you deserve to fully understand every aspect of your care. If something about your diagnosis, treatments, medications, or symptom progression isn't clear—ask. Seeking clarification helps ensure you have the information needed to make informed decisions and take an active role in your care. There are no "wrong" questions when it comes to your health and well-being, and your healthcare team is there to provide guidance. Remember that under the *Health Care Consent Act*[33] in Canada, you have the right to informed consent, meaning you should never hesitate to ask questions to fully understand your options. If you feel rushed or unsure during your appointment, try taking notes and writing down your

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[33] *Health Care Consent Act*, 1996, S.O. 1996, c. 2, Sched. A.

questions as they come up. If you don't get a chance to ask them right away, you'll have them ready for your next visit. The more you understand, the more confident and in control you'll feel in managing your Parkinson's journey.

5. Consider Having a Support Person to Help Advocate for You at Appointments

If you feel anxious, overwhelmed, or unsure about raising your questions and concerns during appointments, consider bringing a trusted friend, family member, or caregiver with you. Having a support person can help you feel more confident in advocating for your needs and ensure that important topics don't get overlooked. They can take notes, ask clarifying questions, and help you remember key details from medical discussions. Beyond practical support, an advocate also provides emotional reassurance, making your appointments feel less stressful and more productive.

6. Explore Different Treatment Options

Reputable Parkinson's organizations, such as Parkinson Society Southwestern Ontario (PSSO), the Parkinson's Foundation, the Michael J. Fox Foundation, and more provide credible information on the different treatment approaches that have proven beneficial for different individuals managing Parkinson's. These organizations highlight therapies such as yoga for improving balance and flexibility, while others benefit from speech therapy, physiotherapy, and even music and dance therapy. Others have experienced relief through alternative approaches such as acupuncture or massage therapy.

Having an open mind and a willingness to try different approaches can help you take an active role in your treatment plan and symptom management. What works for one person may not work for another, so exploring different therapies allows you to discover what best works for you. However, be sure to speak with your healthcare team before trying new treatments to ensure they are safe and appropriate for your specific needs.

See:

- Parkinson's Foundation's "Treatment" webpage
- Michael J. Fox Foundation's "Medication & Treatments" webpage
- Parkinson's UK's "Treatment and Therapies for Parkinson's" webpage
- American Parkinson Disease Association "Treatment Options for Parkinson's" webpage

GETTING CONNECTED

Living with Parkinson's can sometimes feel isolating, but building a support network can help you take an active role in your healthcare while also looking after your mental well-being. Connecting with others—whether through support groups, online communities, or local organizations—provides emotional support, reduces feelings of isolation, and helps you navigate challenges with others who understand your experience.

Beyond emotional support, being part of a community also allows you to learn from others about how they advocate for themselves, what treatments or symptom management strategies have worked for them, and how they navigate the healthcare system. Hearing different perspectives can empower you to make informed choices, ask better questions at medical appointments, and explore new approaches to managing Parkinson's.

Parkinson Society Southwestern Ontario (PSSO) understands the importance of connection and community for those living with Parkinson's. PSSO strives to bridge the gap in care by providing individuals diagnosed with Parkinson's, as well as their care partners, with the information, support, and resources they need at any stage of the disease's progression. Through the GETTING CONNECTED Parkinson's Referral Program, PSSO connects individuals to community-based programs, educational opportunities, and ongoing support services.

You can fill out PSSO's GETTING CONNECTED Parkinson's Referral Program form here to get connected to these essential resources.

OTHER RESOURCES

There are many resources available to support you on your Parkinson's journey, from physical therapy programs to community support groups. These resources exist for a reason—they can provide crucial guidance, connect you with experts, and help improve your quality of life.

To find resources near you, join PSSO's "GETTING CONNECTED" Program here, explore Parkinson Canada's CareFinder system here, or conduct your own research to discover local support tailored to your needs.

Family/Caregiver Resources

1. **Parkinson Society Southwestern Ontario's PEP (Parkinson's Education Program) Online**

- PEP Online is an eight-module educational program designed for caregivers and healthcare professionals providing care to individuals with moderate to severe Parkinson's in community settings
- Participants gain knowledge on Parkinson's symptoms, treatment options, medication management, mobility and safety strategies, communication deficits, emotional and psychiatric support, and more.

2. **Ontario Caregiver Coalition**
    - Advocacy organization that caregivers can join
    - "Mission to improve lives of caregivers by advocating for fair access to needed support"

3. **Ontario Caregiver Organization**
    - Provides a variety of resources and support options for caregivers
    - Counselling programs, mental health support, peer support, e-learning courses
    - Special resources for caregivers that belong to certain communities (2SLGBTQIA+, Black, Indigenous, Young)
    - Tools for caregivers

4. **CareChannel**
    - Online portal with free resources
    - Articles and resources for topics like "what to do when they refuse help, will and power of attorney, grieving strategies, overcoming worry"

5. **Right at Home Canada**
    - Provides specialty home care services and support to help relieve caregiver burden

6. **Parkinson Canada**
    - Website has webinars, articles and other resources for individuals living with Parkinson's and their families
    - CareFinder feature which is an online directory that connects you with services based on your location

7. **Senior Helpers**
    - Provides specialized care
    - Providers are trained in parkinson's disease care

Not-for-Profit Resources

1. **Parkinson Canada**
    - Offers free information and referrals to services and programs for people with Parkinson's, their caregivers, and healthcare professionals. They also offer webinars, support groups, and an online directory.

- The Parkinson Canada Information and Referral Helpline is a toll-free Canada-wide number for people living with Parkinson’s, their caregivers and health care professionals. They provide free and confidential non-medical information and referral services.
- Partners with and supports exercise and wellness programs that are specifically tailored to people living with Parkinson’s.
- Offers free educational publications about Parkinson’s.
- Hosts local peer support groups in people’s communities to provide mutual support from other people living with Parkinson’s Disease. Support groups offer a safe environment for talking about their experiences, enhancing their ability to cope with the daily challenges of Parkinson’s.
- The webinars help both people living with Parkinson’s and their families understand Parkinson’s disease.

2. **Parkinson's Foundation**
    - Provides information on living with Parkinson's disease, including medical issues, symptoms, and treatments. They also offer a helpline staffed by nurses, social workers, and health educators.

3. **Davis Phinney Foundation**
    - Provides information, tools, and funding for early-phase research.

4. **Michael J. Fox Foundation**
    - Provides information on diagnosis and symptoms, life with Parkinson's disease, and more.