



Parkinson Canada

Advocacy Toolkit

parkinson.ca

KEY PARKINSON'S FACTS IN CANADA

110K

More than 110,000 people live with Parkinson's in Canada.

53%

of people with Parkinson's surveyed had to stop working or retire earlier than planned due to Parkinson's.

41%

Care partners saw an average income decline of 41%.

92%

of care partners saw an income decline after taking on care responsibilities.

90%

90% of costs are borne by those affected by Parkinson's and their care partners.

3.3B

In 2024, the estimated cost of Parkinson's in Canada is \$3.3 billion, expected to reach \$4.4 billion by 2034.

For more information and data, please visit parkinsonpricetag.ca and view our full report on *The Economic Burden of Parkinson's in Canada*.

Considerations when interacting with your elected officials

1. Elected officials are very busy as they are meeting with as many constituents as possible. Elected officials may or may not be able to take a one-to-one meeting. If your elected official agrees to a meeting, be prepared and expect to have no more than 15-30 minutes with them.
2. Meetings are not the only way to get time with an elected official. Check the news or their website for local events they will be attending. Local events can be a great opportunity for you to introduce yourself and briefly share your issues and concerns. Remember to be prepared and concise with what you want to say. Sign up for their local newsletters to receive updates on their activities.
3. As a charitable organization, Parkinson Canada is *nonpartisan*. This means that we engage with all parties and their members without bias. When advocating on our behalf, please refrain from showing support or favour for one party over another.

Suggested agenda for meeting with elected officials

1. Introductions
 - Share your connection to Parkinson's.
 - Ask if they have a connection to Parkinson's or familiarity with the condition.
2. Parkinson's in Canada and request
 - Share key information on Parkinson's by highlighting some main points that were mentioned on page 1.
 - Request their commitment to make Parkinson's a priority and to ensure that improved health care is seen as important.
 - Make it personal by providing your main points on why this is important as it relates to your personal experience.
3. Questions to ask your elected officials
 - Refer to the strategic asks from below, or use some of these sample questions:
 - How do you and your party intend to improve the lives of people living with Parkinson's?
 - How do you and your party intend to improve access to care for those with Parkinson's?
 - How do you and your party intend to provide more support to informal care partners?
 - Will you share this support publicly by posting on social media with the #PrioritizeParkinsons hashtag?
4. Thank them for their time and let them know you will follow up!

Strategic asks for your elected officials

The objective of outreach to your elected officials, including meetings and letters, is to build a relationship with the official while raising awareness about Parkinson's and to find areas of shared priorities. Consider raising the following questions when engaging with elected officials:

1. Ask what measures their party intends to take for people living with Parkinson's to have access to medicines that can help manage symptoms.
2. Ask how their party intends to improve access to disability supports to allow those living with Parkinson's to manage the additional financial burden of living with a chronic condition.
3. Request that the elected official show their support for what you have discussed by sharing a message on social media emphasizing the importance of improving health care for those living with Parkinson's in Canada, using the #PrioritizeParkinsons hashtag.
4. Ask the elected official to learn more about Parkinson's. A great place for them to start is our website www.parkinson.ca or by emailing advocacy@parkinson.ca.
5. Request that the elected official share what they have learned on the need for improved health care outcomes for people with Parkinson's with their party.

SOCIAL MEDIA POST EXAMPLES



Projections suggest that by 2031, the number of Canadians over 40 living with Parkinson's will increase by 65%, reaching approximately 163,700 individuals. #PrioritizeParkinsons



53% of people with Parkinson's surveyed reported needing to retire earlier than planned while also facing high out-of-pocket costs to manage their symptoms. I'm raising awareness of Parkinson's and I ask that you join me! #PrioritizeParkinsons



There are over 110,000 people living with Parkinson's in Canada, and the number is continuing to rise each year. The time is now to ensure equitable, timely, and affordable access to care. #PrioritizeParkinsons



33% of people with Parkinson's surveyed experienced a salary decrease of 20% or more when compared to their salary pre-diagnosis. We need fair financial support now! #PrioritizeParkinsons



87% of care partners surveyed are supporting someone with Parkinson's without compensation. Without proper support, care partners will burn out. Care partners deserve recognition and support! #PrioritizeParkinsons



In 2024, the total cost of Parkinson's in Canada is estimated at \$3.3 billion. People with Parkinson's and their care partners bear approximately 90% of these costs. Parkinson's must be a policy priority! #PrioritizeParkinsons

Tips for writing an effective letter and emails to elected officials

Address your letter correctly. Be sure you have the correct address and salutation in your letter. Also be sure to double check the spelling of the person's name. It's always best to err on the side of being formal with your correspondence with someone in political office, as this shows respect and builds stronger relations.

Only address one issue per letter. Being concise on one specific topic will make for a quicker and more impactful ask and response.

Be accurate. Beware of false or misleading information. Always double-check if you are not sure!

Make a specific ask. Make sure to ask your elected official to act. Whether it is asking for a meeting, a phone call, to support a bill, or a current initiative; always ask for their position on the issue you are addressing.

Make it personal. Share your story and how it affects you. Tie in your own experience and expertise using your own words.

Be polite and courteous. Rudeness or aggressiveness is sure to alienate the reader.

Be concise. Keep your letter as short as possible to ensure that your message is fully read. For letters, it should be no longer than one typed page. If sending an email, no more than 3-5 paragraphs is ideal.

Include your return address in your letter. Even in an email, always include your address so that the elected official knows that you live in the riding they represent. Make sure your elected official knows how to reach you and include your phone number if you are comfortable.

Express appreciation. Thank them for their time and consideration and add a note about another initiative that they may have taken part in to show that you are following their activities.

Follow up. Elected officials are busy and it may take weeks to respond. Follow up via phone or email to confirm that they received your letter if you have not received a timely response. When you do receive a response, send a follow-up thank-you letter and ask follow-up questions if they provided unsatisfactory responses. Follow-up letters often have a much larger impact than the initial communication as the elected official will recognize the importance of the issue to you.

SAMPLE EMAILS TO ELECTED OFFICIALS

1. Use this email template for meeting requests:

Dear first and last name,

My name is [name]. I am a resident in the riding of [name of riding]. I have been [describe if you have been living with Parkinson's, caring for someone living with Parkinson's, and for how long].

As a supporter of the Parkinson's community and in partnership with Parkinson Canada, I am requesting to meet with you to discuss the need for the government to make Parkinson's a priority and commit to improving healthcare for those living with Parkinson's in Canada.

Thank you in advance for your response. I look forward to meeting with you.

[Signed]

[Your Address]

SAMPLE EMAILS TO ELECTED OFFICIALS

2. Use this email template if you are unable to meet with your elected official but would like to share your story and requests with them:

Dear first and last name,

My name is [first name, last name]. I am a resident in the riding of [name of riding]. I have been [living with Parkinson's for X years/month/caring for my [RELATION TO PERSON LIVING WITH PARKINSON'S] with Parkinson's for X years/months].

During this time, I have experienced [add personal challenges with accessing care/services].

As a supporter of the Parkinson's community and Parkinson Canada, I want to bring your attention to the urgent need to make Parkinson's a priority and seek your commitment to improving health care for the Parkinson's community.

I would like you to consider the following questions:

1. How do you intend to improve the lives of people living with Parkinson's in Canada?
2. What measures does your party intend to take for Canadians to have equitable and affordable access to care?
3. How does your party intend to improve access to disability supports for people living with Parkinson's in Canada?
4. Can I count on you to commit to making Parkinson's a priority?
5. Will you write a letter to your party leadership requesting their commitment to make Parkinson's a health care priority?

Thank you in advance for your response.

[Signed]

[Your Address]

ABOUT PARKINSON CANADA

At Parkinson Canada, people with Parkinson's are at the centre of everything we do. We empower the Parkinson's community through tailored programs, innovative research and raising the voice of people affected by Parkinson's across Canada.

As a national registered charity, Parkinson Canada fulfils its mission through the generosity of donors and is an accredited organization under the Imagine Canada Standards Program.

Please visit parkinson.ca, call **1-800-565-3000**, or email info@parkinson.ca in English or French for more information.

