



Information About the Questionnaire

A survey on Parkinson's disease and access to healthcare services

Information

You are being asked to participate in a research study that we are conducting on Parkinson's disease and access to healthcare.

The goal of this study is to better understand how people living with Parkinson's disease access healthcare services across Canada and Europe. We are inviting people living with Parkinson's disease to complete a questionnaire. The information collected in this survey will help us to understand barriers to accessing care for people living with Parkinson's disease and inform the development of strategies to improve access to care.

Your decision to participate is voluntary. Some questions may make you feel uncomfortable due to their personal nature. You may refuse to answer any questions that make you uncomfortable or stop completing the questionnaire at any time. Please note however that the data from partially completed questionnaires will still be used. Whatever you choose, it will not affect the usual medical care that you receive.

The questionnaire should take about 15 minutes to complete. You may complete part of the questionnaire and then come back later to finish it.

Before you decide to participate, you should know that the questionnaire contains personal health questions. We work under ethical regulations guiding privacy when collecting, using and disclosing information. Only those involved in conducting and analyzing the survey will see this information. The questionnaire is anonymous and all personal information will be kept confidential. Please note that even if you decide not to complete the survey, it will be impossible to withdraw the data due to participant anonymity.

For any questions about this study, please contact:

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If you have questions about your rights as a participant or about ethical issues related to this study, you can talk to someone who is not involved in the study at all. Please contact The Ottawa Health Science Network Research Ethics Board, Chairperson at 613-798-5555 extension 16719, use reference number 20200463-01H.

Eligibility Questions

Eligibility questions

Please select the box that best reflects your relationship with Parkinson's disease.

- I have been diagnosed with Parkinson's disease
- I am a caregiver, family member or friend willing to provide someone diagnosed with Parkinson's disease assistance to complete the questionnaire
- I have never been diagnosed with Parkinson's disease nor am I willing to provide assistance to complete the questionnaire for someone who has been diagnosed with Parkinson's disease

It is important, to the extent that it is possible, that individuals living with Parkinson's complete the questionnaire. If needed, please ask a caregiver, family member or friend for assistance. It will take approximately 15 minutes to complete the questionnaire.

Do you agree to participate?

- Yes

No

Since you have indicated that you have never been diagnosed with Parkinson's disease nor are you willing to provide assistance to complete the questionnaire for someone who has been diagnosed with Parkinson's disease, this survey does not apply to you.

Instructions for Filling out the Questionnaire

Instructions for filling out the questionnaire

Please answer each question by clicking on the response that best reflects your opinion or experience.

There are no 'right' or 'wrong' answers. Your views and experiences are what matter.

It is important, to the extent that it is possible, that it is the individuals living with Parkinson's who answer the survey questions. If needed, a caregiver or family member can provide assistance.

Section A: Your Health

Section A: Your health

First, we would like to ask you a few questions about your health.

When were you first diagnosed with Parkinson's Disease?

- Less than 2 years ago
- 2 to 5 years ago
- 6 to 10 years ago
- 11 to 15 years ago
- 15 or more years ago

Parkinson's disease stages correspond both to the severity of movement symptoms and to how much the disease affects daily activities. To the best of your knowledge, what is your current Parkinson's disease stage?

- Stage One (early stage):** Mild symptoms that generally do not interfere with daily activities. Tremor and other movement symptoms occur on one side of the body only. Changes in posture, walking and facial expressions occur.
- Stage Two (early to mid-stage):** Symptoms start getting worse. Tremor, rigidity and other movement symptoms affect both sides of the body. Walking problems and poor posture may be apparent. The person is still able to live alone, but daily tasks are more difficult and lengthy.
- Stage Three (mid-stage):** Loss of balance and slowness of movements are hallmarks. Falls are more common. The person is still fully independent, but symptoms significantly impair activities such as dressing and eating.
- Stage Four (mid- to advanced stage):** Symptoms are severe and limiting. It's possible to stand without assistance, but movement may require a walker. The person needs help with activities of daily living and is unable to live alone.
- Stage Five (advanced stage):** Stiffness in the legs may make it impossible to stand or walk. The person requires a wheelchair or is bedridden. Around-the-clock nursing care is required for all activities.

Many people with Parkinson's disease report problems from time to time. We are interested in how you have been in your general health over the last four (4) weeks. Please complete the following questions by selecting one box on each line. **Over the past four (4) weeks have you, because of Parkinson's disease...**

	Never	Sometimes	About half the time	Most of the time	Always
...had difficulty getting around in public <input type="radio"/> places?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
...had difficulty dressing yourself?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...felt depressed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...had problems with close relationships?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...had problems with concentration?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...felt unable to communicate properly?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...had painful muscle cramps and pains?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...felt embarrassed about having <input type="radio"/> Parkinson's disease?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	

Apart from Parkinson's disease, do you have any other significant health conditions?

- Yes
 No

Please specify your other significant health conditions?

1.

2.

3.

4.

Section B: Your experiences with healthcare services before the COVID19 pandemic

Section B: Your experiences with healthcare services before the COVID-19 pandemic

Now we would like to ask you a few questions about your healthcare providers and the care you received. **Here we are particularly interested in your typical healthcare experiences in the year or so (i.e. 12 months) before the COVID-19 pandemic.**

Do you have a regular caregiver? By caregiver, we mean a spouse or other family member, friend, or paid helper who who you rely on for day-to-day activities such as bathing, grooming, dressing, exercise, food preparation, and cleaning.

Yes

No

Who is your regular caregiver? *Select all that apply*

- Spouse/partner
- Other relative (sister, brother etc.)
- Friend
- Paid caregiver
- Other, please specify

Does your caregiver go with you to medical appointments?

- Never
- Rarely
- Sometimes
- Often
- Always

Does your caregiver help you to communicate during medical appointments?

- Never
- Rarely
- Sometimes
- Often
- Always

Block 6

In the 12 months prior to the COVID-19 pandemic, approximately how often did you see a Family Physician

for reasons related to Parkinson's disease?

- 0 times
- 1 or 2 times
- 3 to 6 times
- Monthly
- More than monthly
- Don't know

How would you rate this Family Physician's knowledge of Parkinson's disease?

- Excellent
- Very good
- Good
- Fair
- Poor
- Don't know

In the 12 months prior to the COVID-19 pandemic, how often did you see a neurologist for reasons related to Parkinson's disease?

- 0 times
- 1 or 2 times
- 3 to 6 times
- Monthly
- More than monthly
- I don't know

How would you rate your neurologist's knowledge of Parkinson's disease?

- Excellent
- Very good
- Good
- Fair
- Poor
- Don't know

Block 7

In the 12 months prior to the COVID-19 pandemic, which of the following other healthcare provider did you visit for reasons related to Parkinson's disease? *Select all that apply*

- Mental health worker
- Social worker
- Physical therapist
- Occupational therapist
- Speech therapist
- Other, specify
- None

If several healthcare providers have been involved in your treatment, did they work together to coordinate your treatment plan?

- Yes, to a great extent
- Yes, to a moderate extent
- Yes, to some extent
- No, not at all
- Don't know
- Not applicable

In the 12 months prior to the COVID-19 pandemic, when you needed to access healthcare services, which of the following geographical barriers did you face? *Select all that apply*

- Service only available in another city/town
- Service only available in another region
- Service only available in another country
- None of the above

To overcome this geographical barrier, did you have access to: *Select all that apply*

- A source of transportation
- Financial support (e.g. for travel)
- An eHealth or telemedicine service (i.e. video conference or telephone)
- Other, please specify
- Unable to access the service because of the barrier

What services or resources for people with Parkinson's are available in your community or local area?

Select all that apply

- Neurologists
- Family Physicians
- Nurse practitioners
- Support groups
- Transportation services
- In-home support to complete household tasks (e.g. laundry, cleaning, cooking)
- Home care (e.g. personal support for daily living activities)
- Physiotherapy
- Occupational therapy

- Nutritional/dietary counselling
- Physical activities/exercise programs
- Assistance in applying for government financial support
- Speech-language therapy
- Massage therapy
- Other, please specify
- No services or resources are available
- Don't know

Block 8

In the 12 months prior to the COVID-19 pandemic, how often did you feel that you needed healthcare services for Parkinson's disease but did not receive it?

- Never, you always received the healthcare services you needed
- Rarely
- Sometimes
- Often
- Always

Of the services and resources available in your community or local area, are there any that you feel you needed but were unable to access in the 12 months prior to the COVID-19 pandemic? *Select all that apply*

- Neurologists
- Family Physicians
- Nurse practitioners
- Support groups
- Transportation services
- In home support to complete household tasks (e.g. laundry, cleaning, cooking)

- Home care (e.g. personal support for daily living activities)
- Physiotherapy
- Occupational therapy
- Nutritional/dietary counselling
- Physical activities/exercise programs
- Assistance in applying for government financial support
- Speech-language therapy
- Massage therapy
- Other, please specify
- No, all of these services and resources are accessible

What barrier(s) prevented you from receiving the healthcare services you needed? *Select all that apply*

- Difficulty getting a referral
- Difficulty getting an appointment
- Unable to leave the house because of a health problem
- Unable to find someone to accompany you
- Service not available in community or local area
- Wait times too long between booking appointment and visit
- Wait times in waiting room too long
- Appointment cancelled or deferred
- Felt you would receive inadequate care
- Direct cost of the visit (i.e. fee for the consultation)
- Indirect costs related to the visit (i.e. travel, accommodation, etc.)
- Physician didn't think it was necessary
- Transportation problems
- Problem with health insurance
- Personal or family responsibilities
- Language problems
- General deterioration of health
- Other, please specify

In the 12 months prior to the COVID-19 pandemic, how difficult or easy was it to obtain the healthcare services you needed for Parkinson's disease?

- Very difficult
- Somewhat difficult
- Somewhat easy
- Very Easy

In the 12 months prior to the COVID-19 pandemic, how often did you forgo or postpone healthcare visits or treatment because of cost? (Note: these may be direct costs for tests, prescriptions or treatments for example OR indirect costs related to transportation, time off work for you or a caregiver etc.)

- Never
- 1 time
- 2 to 3 times
- 4 or more times

Do you have extended (private or public) health insurance to help cover your healthcare and medication costs?

- Yes
- No
- Don't know

How often do you experience financial difficulties as a result of costs related to healthcare visits or treatment?

- Never
- Rarely
- Sometimes
- Often
- Always

Thinking about the last time you saw a healthcare provider prior to the COVID-19 pandemic, did you experience any difficulties or barriers communicating with them?

- Yes
- No

Were these difficulties or barriers due to: *Select all that apply*

- Anxiety
- Embarrassment
- Difficulty finding words
- Difficulties remembering information
- Speech-related problems
- Difficulty concentrating
- Felt rushed by the physician
- Felt that the physician didn't understand your problems
- Felt that the physician was impatient with you
- Other difficulties, please specify

Have you ever felt stigmatized when seeking or receiving healthcare services because of: *Select all that apply*

- Your young age
- Your older age
- Your physical disabilities
- Your intellectual disabilities
- Your mental health status
- Your chronic/long term condition
- Your ethnicity
- Being a woman
- Being a man
- Being transgender
- Your income/social status
- Your religion
- Your sexual orientation
- Other, specify
- No, have never felt stigmatized

Do you think that barriers to accessing healthcare services have affected your health or other aspects of your life in any way?

- Yes
- No

How was your life affected as a result of barriers to accessing healthcare services? *Select all that apply*

- Worry, anxiety, stress
- Worry or stress for family or friends
- Pain
- Problems with activities of daily living (e.g., dressing, driving)
- Loss of work
- Loss of income

- Increased dependence on relatives/friends
- Increased use of over-the-counter drugs
- Overall health deteriorated, condition got worse
- Personal relationships suffered
- Other, please specify

In the 12 months prior to the COVID-19 pandemic, overall, how satisfied are you with the way healthcare services related to Parkinson's disease were provided?

- Very satisfied
- Somewhat satisfied
- Somewhat dissatisfied
- Very dissatisfied

Section C: Access to healthcare services and COVID-19

Section C: Access to healthcare services and COVID-19

We would like to ask a few questions about how COVID-19 has affected your access to healthcare services for Parkinson's disease related care.

Prior to the COVID-19 pandemic, how often were your Parkinson's disease related healthcare visits conducted remotely (i.e. by phone or video conference)?

- Never

- Rarely
- Sometimes
- Often
- Always

During the COVID-19 pandemic, have you had a Parkinson's disease related healthcare visit conducted remotely (i.e. by phone or video conference)?

- Yes
- No

If yes, **during the COVID-19 pandemic**, approximately how many Parkinson's disease related healthcare visits been conducted remotely?

- 1
- 2- 3
- 4-5
- More than 5

How are your remote healthcare visits typically conducted?

- By telephone
- By video conference
- Other, please specify

Please indicate the extent to which you agree or disagree with the following statements, as they relate to

healthcare visits conducted remotely (i.e. by telephone, video conference or other):

	Strongly agree	Somewhat agree	Somewhat disagree	Strongly disagree	Don't know
I feel comfortable with the technology used to consult with my healthcare providers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have access to the technology I need to consult with my healthcare providers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I can get assistance with the technology used to consult with my healthcare providers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please indicate the extent to which you agree or disagree with the following statements, as they relate to healthcare visits conducted remotely (i.e. by telephone, video conference or other):

	Strongly agree	Somewhat agree	Somewhat disagree	Strongly disagree	Don't know
I am confident that healthcare providers can accurately assess my medication/treatment <u>remotely</u>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am confident that healthcare providers can accurately assess my condition <u>remotely</u>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I am confident that I can access all of the services I need remotely



Since the beginning of the COVID-19 pandemic how often did you feel you needed healthcare for Parkinson's disease but did not receive it?

- Never, you always received the healthcare services you needed
- Rarely
- Sometimes
- Often
- Always
- Not applicable, you did not need care since the beginning of COVID-19 pandemic

Thinking of the most recent time you felt this way, why did you not receive the care you needed? (Please specify)

Since the beginning of the COVID-19 pandemic, how difficult or easy was it to obtain the healthcare services you needed for Parkinson's disease?

- Very difficult
- Somewhat difficult
- Somewhat easy
- Very Easy

Since the beginning of the COVID-19 pandemic, how satisfied are you with the way healthcare services related to Parkinson's disease are provided?

- Very satisfied
- Somewhat satisfied
- Somewhat dissatisfied
- Very dissatisfied

Considering the challenges of social distancing as well as other preventative measures aimed at minimizing the spread of COVID-19, please suggest any ideas that you may have to improve access to care for people with Parkinson's disease.

Block 9

Section D: Demographic and socioeconomic characteristics

The final questions are to learn more about you and your household. Please be assured that this information will be kept confidential.

In what year were you born?

What is your gender?

In what country were you born?

- Canada
- Other, please specify

In what year did you come to Canada?

Which of the following best describes your ethnic or racial background? *Select all that apply*

- Caucasian or white (e.g. British, French, Italian, Ukrainian)
- East Asian (e.g. Chinese, Korean, Japanese)
- South Asian (e.g. East Indian, Pakistani, Sri Lankan)
- Black (e.g. African, Caribbean, North American)
- Indigenous (e.g. First Nations, Inuit, Métis, non-status)
- Latin, Central or South American (e.g. Mexican, Brazilian, Costa Rican)
- Southeast Asian (e.g. Vietnamese, Cambodian, Filipino)

West Asian or Arab (e.g. Egyptian, Saudi Arabian, Iranian, Afghani)

Other, please specify

What language do you primarily speak at home?

English

French

Other language, please specify

What is your marital status?

Single, never married

Married or common-law relationship

Widowed

Divorced

Separated

What kind of community do you live in?

Big city (i.e. more than 300,000 people)

Suburbs of a big city

Town or small city

Country village

Farm or countryside

Other, please specify

Choose what best reflects your current living situation?

- Live alone
- Live alone with another person (e.g. spouse, sibling, friend, etc.)
- Live in a retirement home
- Live in a nursing home (i.e. skilled care facility)
- Other, please specify

What is the highest level of schooling that you have completed?

- Grade 8 or less
- Some high school
- High school diploma
- Some trade, technical school, community college, CEGEP, business college
- Diploma or certificate - trade, technical school, community college, CEGEP, business college
- Some university
- Bachelor's Degree
- Graduate degree
- Graduated from vocational school
- Other, please specify

Which of the following best describes the combined annual before-tax income of all persons in your household?

- Under \$20,000
- \$20,000 to under \$40,000
- \$40,000 to under \$70,000
- \$70,000 to under \$100,000

- \$100,000 to under \$130,000
- \$130,000 to under \$160,000
- \$160,000 or more
- Prefer not to answer

To what extent would you say that you and your family are able to make ends meet (i.e. get by financially):

- All of the time
- Most of the time
- Some of the time
- Rarely
- Never
- Don't know

What province or territory do you live in?

- British Columbia
- Alberta
- Saskatchewan
- Manitoba
- Ontario
- Quebec
- New Brunswick
- Nova Scotia
- Prince Edward Island
- Newfoundland and Labrador
- Yukon
- Northwest Territories
- Nunavut

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