

# Parkinson's Disease Healthcare Survey

*This survey is about your experiences of health services for Parkinson's disease in Ireland.*

Please fill out this survey and return to us in the pre-paid envelopes provided.

## Who is filling out this survey?

A person living with Parkinson's disease (PD)

A family member/friend on behalf of someone with PD

A person with PD and a family member/friend completing the survey together

A healthcare professional on behalf of/with a person with PD

Other (Please Indicate) \_\_\_\_\_

## Section 1: Information about the person living with Parkinson's disease:

### Gender:

Male  Female  Non-binary  Transgender  Prefer not to say  Other

### Age Group:

≤ 20 years

21-39 years

40-44 years

45-49 years

50-54 years

55-59 years

60-64 years

65-69 years

70-74 years

75-79 years

80-84 years

85-89 years

90+years

### Please indicate your ethnicity (choose the option that best describes you):

White Irish

Irish Traveller

Any other white background

Black Irish

Black (any other background)

Asian Irish

Asian (any other background)

Mixed ethnicity

Other (please specify) \_\_\_\_\_

### Please indicate where you reside:

Own home (living alone)

Own home (with spouse/family)

With relative(s) in their home

A care home/nursing home

A relative's home

Care Home

Other (please specify) \_\_\_\_\_

**Do you speak a language other than English or Irish at home?**

Yes  No

**If you answered 'no', How well do you speak English?**

Very well  Well  Not well  Not at all

**Where is your residence located?**

A) In a City  In a Village/Town  In a Rural Area

**In what province is your residence located?**

B) Munster  Connaught  Ulster  Leinster

**Relationship status:**

Married/long term partner  Widowed  Separated/Divorced

Single (never married)  Other (please specify)  \_\_\_\_\_

**Current employment status:**

Employed  Retired  Self-employed  Unemployed

Home Maker  Unable to work due to illness/disability

**We want to be inclusive of the LGBT+ community, to better understand the healthcare needs of this community. If you feel comfortable to do so, please state your sexual orientation:**

Heterosexual  Homosexual (i.e. gay, lesbian)  Bisexual  Prefer not to say

**Wellbeing**

Overall, how would you rate your:

A) Physical wellbeing: Very good  Good  Poor  Very Poor

B) Mental wellbeing: Very good  Good  Poor  Very Poor

**Tobacco smoking behaviour:**

I smoke daily  I smoke, but not daily  Ex-smoker  Never smoked

**Daily smoking behaviour:**

I smoke more than 20 cigarettes a day  I smoke 10-20 cigarettes a day

I smoke less than 10 cigarettes a day  Not applicable

**Ex-Smoker:**

Ex heavy smoker (20+ per day)  Ex-smoker (less than 20/day)  Not applicable

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## Section 2: Information about your Parkinson's disease

### How long has it been since you received your diagnosis?

Less than 1 year  1-5 years  6-10 years  11-15 years  >15 years

### Are you currently on either of the following schemes?

General Medical Scheme (you have a valid medical card) Yes  No  I'm not sure

Long-Term Illness Scheme (for your Parkinson's) Yes  No  I'm not sure

### Are you currently taking Parkinson's disease medications?

Yes  No

### If you are not taking Parkinson's medications, can you briefly explain why (otherwise skip)

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### If 'yes', do you currently use any of the following medications? (tick all that apply)

Levodopa (e.g. Sinemet, Madopar)

Dopamine Agonist (e.g. Mirapexin, Requip, or Neupro patch)

MAO-B inhibitor (e.g. Azilect)

Anticholinergic (e.g. Kemadrin, Akineton)

Apomorphine Pump (under skin)

Apomorphine rescue injections

Duodopa pump (PEG tube)

Other  (Please indicate) \_\_\_\_\_

### Do you have to pay for any of your Parkinson's medications?

All of them  Some of them  None of them

If yes, how much on average per month do they cost you € \_\_\_\_\_

**Have you ever been assessed to see if you would be suitable for Deep Brain Stimulation?**

Yes  No

**Have you had Deep Brain Stimulation treatment abroad?**

Yes  No

**When your treatments are working at their best, how well do you move? (choose the answer that best describes you)**

I move normally for my age

I can do most things without difficulty, but I'm a little slow

I can do most things, but with some difficulty

There are some things I cannot do without help/assistance

I need help with most tasks

**Do you currently need a walking aid?**

Yes  No

**Which of the following walking aids do you use? (skip this question if you don't use any aids)**

Cane/Stick

Rollator

Walking frame

Wheelchair

Electric mobility scooter

Other: \_\_\_\_\_

**Section 3: Information about informal carer / care partner**

In this section we wish to know if there is a person (family member/friend/neighbour, etc) who supports the person with PD in their everyday life, on a regular and ongoing basis.

**Do you currently have a 'carer', a 'care partner' or someone who supports you in your daily life?**

Yes

No, but I would like more support

No, I don't need a carer

**Carer gender:**

Male

Female

Non-binary

Transgender

Prefer not to say

**Does the carer live with the person with Parkinson's?**

Yes (full-time)

Yes (some of the time)

No

**Carer's Relationship to the person with Parkinson's disease:**

Spouse

Daughter/Son

Daughter-in-law/Son-in law

Other Relative

Friend/Neighbour

Other  (Please indicate) \_\_\_\_\_

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## Section 4: Healthcare services for Parkinson's Disease in Ireland

### Who officially diagnosed you with Parkinson's disease?

GP       Neurologist(public)       Neurologist(private)       Geriatrician (public)   
Geriatrician (private )       Other  (Please indicate) \_\_\_\_\_

### How long did it take to get your diagnosis from when you first sought help for your symptoms?

≤ 1 month       2-3 months       4-5 months       6-7 months   
8- 9 months       10-12 months       More than 12 months

### If you think there was an undue delay in our diagnosis, can you briefly say why you think that was? (Please skip this question if you don't think this applies to you)

### Do you think that the way that your diagnosis was disclosed to you was acceptable?

Yes       No

### People with PD have reported very different experiences of receiving their diagnosis. If you want to say anything about how your diagnosis was disclosed to you, you can do so in the box below (if not, you can go to the next section)

**In the weeks following diagnosis, did a health professional contact you to check how you were doing? (e.g. Nurse, Consultant, GP)**

Yes  No

**Have you ever considered getting a 'second opinion' about your Parkinson's diagnosis?**

Yes  No

If you answered 'yes can you say why?

**Which of the following healthcare professionals do you attend to manage your Parkinson's disease? (tick all that apply)**

GP  Neurologist  Geriatrician  PD nurse specialist

Other(s)  (Please indicate) \_\_\_\_\_

**Do you have a main point of contact for your Parkinson's disease needs (i.e. a healthcare professional that you can ring at any time)?**

Yes  No

If you indicated that you do have a main point of contact, please state which type of health professional this is (Otherwise continue to the next section)

\_\_\_\_\_

**Is the clinic that you attend for your Parkinson's disease:**

A general Neurology clinic  A general Geriatric Medicine clinic

A specialist Parkinson's clinic  I don't know

**Is the clinic that you attend for your Parkinson's disease:**

Public  Private

**Is the clinic that you attend for your Parkinson's disease:**

In a hospital setting  Elsewhere in the community

**How do you typically travel to the clinic?**

By car  Public Transport  Taxi  Walk

**Approximately how far do you have to travel to get to the clinic?**

\_\_\_\_\_ Kilometres

**How long does it take you to get to the clinic?**

\_\_\_\_\_ Hour(s) \_\_\_\_\_ Minutes

**Does someone usually attend the clinic with you?**

Yes, someone usually attends my clinic appointments with me

No, I usually attend my clinic appointments alone

**When you visit the clinic, do you usually see the same doctor?**

Yes  No

**If you see different doctors, can you briefly tell us what you think about this? (skip to the next section if this doesn't apply to you)**

**During your clinic visits, do you typically:**

- |  |                              |                             |                                    |
|--|------------------------------|-----------------------------|------------------------------------|
| A) Get enough time with the doctor?                          | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Sometimes <input type="checkbox"/> |
| B) Feel involved in decisions that are made about your care? | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Sometimes <input type="checkbox"/> |
| C) Feel listened to/understood by staff in the service?      | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Sometimes <input type="checkbox"/> |
| D) Feel like they see you as a person?                       | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Sometimes <input type="checkbox"/> |
| E) Feel your symptoms are adequately assessed?               | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Sometimes <input type="checkbox"/> |

**How often do you attend the clinic for a routine check-up about your Parkinson's?**

At least every 4 months  Every 6 months  Every 9 months

Once a year  Less than yearly

**Would you like more frequent routine check -up visits at the clinic?**

Yes  No

**If you have ever needed to change the date of an appointment, was this facilitated by the clinic?**

Yes, I have been able to change an appointment

No, my appointment couldn't be changed

Not applicable - I have never needed to do this

**If you run into difficulties with your Parkinson's between routine appointments, do you have access to any of the following from the healthcare staff at the clinic?**

- |  |                              |                             |                                       |
|--|------------------------------|-----------------------------|---------------------------------------|
| A) Telephone support                     | Yes <input type="checkbox"/> | No <input type="checkbox"/> | I'm not sure <input type="checkbox"/> |
| B) Videoconference support               | Yes <input type="checkbox"/> | No <input type="checkbox"/> | I'm not sure <input type="checkbox"/> |
| C) An unscheduled review (at the clinic) | Yes <input type="checkbox"/> | No <input type="checkbox"/> | I'm not sure <input type="checkbox"/> |
| D) A home visit                          | Yes <input type="checkbox"/> | No <input type="checkbox"/> | I'm not sure <input type="checkbox"/> |

**Do you usually receive a call between your routine appointments, from a healthcare professional in the clinic, to check in with you?**

Yes  No

If you answered 'no', is this something that you would like to have happen? (otherwise continue to the next section)

Yes  No

**Does your doctor ask you about your medications when you visit the clinic?**

Yes, every time  Sometimes, but not always  No, never

N/A – I am not taking medication for my Parkinson's

**When you are being prescribed a new medication at the clinic, for your Parkinson's, does the doctor do the following?**

- |   |                              |                             |
|---|------------------------------|-----------------------------|
| A) Tell you the reason(s) for the new prescription                      | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| B) Explain the potential side effects associated with the medication    | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| C) Give you an opportunity to ask questions about the medication        | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| D) Tell you about the importance of taking the medication as prescribed | Yes <input type="checkbox"/> | No <input type="checkbox"/> |

**Do you think that the medication(s) that you are currently taking for your Parkinson's are working as they should?**

Yes  No  I'm not sure  Other  \_\_\_\_\_

If you answered 'no' or 'I'm not sure', please briefly indicate why (otherwise skip)

## Section 5: Multidisciplinary Input

Please answer the questions below about services, where they are applicable to you:

### Parkinson's Nurse Specialist

- |   |                              |                             |
|---|------------------------------|-----------------------------|
| 1. There is a PD Nurse Specialist in the clinic I attend: | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 2. I have been offered this service:                      | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 3. I have met with a PD nurse specialist:                 | Yes <input type="checkbox"/> | No <input type="checkbox"/> |

### Physiotherapy

- |  |                              |                             |
|--|------------------------------|-----------------------------|
| 1. There is a physio with PD expertise in the clinic I attend: | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 2. I have been offered this service:                           | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 3. I have been referred to a physio in my locality:            | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 4. I have attended a physio for my PD:                         | Yes <input type="checkbox"/> | No <input type="checkbox"/> |

### Dietician

- |   |                              |                             |
|---|------------------------------|-----------------------------|
| 1. There is a dietician with PD expertise in the clinic I attend: | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 2. I have been offered this service:                              | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 3. I have been referred to a dietician in my locality:            | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 4. I have attended a dietician for my PD:                         | Yes <input type="checkbox"/> | No <input type="checkbox"/> |

### Speech & Language Therapy

- |  |                              |                             |
|--|------------------------------|-----------------------------|
| 1. There is an SLT with PD expertise in the clinic I attend: | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 2. I have been offered this service:                         | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 3. I have been referred to an SLT in my locality:            | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 4. I have attended an SLT for my PD:                         | Yes <input type="checkbox"/> | No <input type="checkbox"/> |

### Occupational Therapy

- |   |                              |                             |
|---|------------------------------|-----------------------------|
| 1. There is an OT with PD expertise in the clinic I attend: | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 2. I have been offered this service:                        | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 3. I have been referred to an OT in my locality:            | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 4. I have attended an OT for my PD:                         | Yes <input type="checkbox"/> | No <input type="checkbox"/> |

### Mental Health Services (e.g. counselling, psychology, psychiatry, social work)

- |  |                              |                             |
|--|------------------------------|-----------------------------|
| 1. There is an SLT with PD expertise in the clinic I attend: | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 2. I have been offered this service:                         | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 3. I have been referred to an SLT in my locality:            | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 4. I have attended an SLT for my PD:                         | Yes <input type="checkbox"/> | No <input type="checkbox"/> |

### Alternative Therapies (Acupuncture, Tai Chi, Reiki, Reflexology, etc.)

1. I have been offered information about alternative therapies    Yes                       No
2. I have used alternative therapies    Yes                       No

### If you have indicated that you would like to use any of the services or therapies above, but have not yet used them, can you tell us why? (tick all that apply)

- A) Not available in my area
- B) Having difficulty getting a referral
- C) Too expensive
- D) They don't have expertise in Parkinson's disease
- E) Other reasons     (Please indicate in the box below):

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## Section 6: Improving services for people with Parkinson's disease in Ireland

### Parkinson's Disease Services & Supports

#### Have you any other thoughts on how we can improve Parkinson's healthcare in Ireland?

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## Section 7: The Parkinson's Association

### Have you heard of the Parkinson's Association of Ireland?

Yes                       No

If you answered 'yes', how did you first hear about the Parkinson's Association? (otherwise skip to the next section)

**Are you a member of your local branch of the Parkinson's Association of Ireland?**

Yes  No

If you answered no, can you tell us why? (Otherwise skip to the next section)

**Do you think the Parkinson's Association provides a valuable service to members?**

Yes  No  I'm not sure

Can you briefly explain your answer?

**From which of the following sources do you get information about managing your Parkinson's?**

- Healthcare professionals
- Family members/Friends
- Internet search engines (e.g. Google, Yahoo, Bing)
- Books about Parkinson's disease
- Social Media (e.g. facebook, twitter)
- Online patient forums/support groups
- Television (e.g. health programmes/documentaries)
- Podcasts
- Radio
- The Parkinson's Association local branches
- Young Parkinson's Ireland
- Other people/families living with Parkinson's
- Other:  \_\_\_\_\_

**The End – Thank You**

**If you have questions about this survey please email [emma.oshea@ucc.ie](mailto:emma.oshea@ucc.ie)**