

Audience: PD Cohort

### **Uncertainty in Parkinson's disease**

People who have been diagnosed with Parkinson's disease (PD) may experience worries, concerns, uncertainties, or fears as they think about their future. This questionnaire aims to better understand your own thoughts about your future with PD.

The survey should take between 10 to 15 minutes to complete. If you are not able to complete it in one sitting, you can return to this survey link, and it will take you to the last question you answered when you resume the survey. Thank you for your interest in completing this survey!

Please click the orange ">>" button to continue.

### **ABOUT YOU**

*Multiple choice, single answer, required*

1. Has a doctor diagnosed you with Parkinson's disease?
  - a) Yes
  - b) No

Skip Logic: If (b. No) is selected for "Has a doctor diagnosed you with Parkinson's disease?", skip to End of Survey thank you 2.

*Multiple choice, single answer, required*

2. How would you rate your overall health?
  - a) Excellent
  - b) Very good
  - c) Good
  - d) Fair
  - e) Poor
  - f) Prefer not to answer

*Multiple choice, single answer, required*

3. Which of the following best describes your current employment status? Please choose the best option.
  - a) Working for pay
  - b) Working without pay
  - c) Self-employed
  - d) Retired
  - e) Unemployed
  - f) Other
  - g) Prefer not to answer

Over the next several pages of this survey, you will be shown examples of different types of worries, concerns, uncertainties, or fears that people with PD may have as they think about how the disease and its symptoms will change over time.

Since everyone's experiences with PD are unique, you may - or may never - have thought about some of issues you will be asked about. Please focus on what your own worries, concerns, uncertainties, or fears have been as you have been thinking about your own future with PD. For the purposes of this questionnaire, we will be referring to these as your "concerns" as you think about the future.

## QUALITY OF LIFE

*Simple matrix, single answer, multiple choice, required*

4. These statements focus on how Parkinson's disease may impact your **quality of life** in the future.

How concerned are you about each of the following when you think about your future with PD?

	I am <b>not at all</b> concerned about this when I think about my future	I am <b>a little</b> concerned about this when I think about my future	I am <b>somewhat</b> concerned about this when I think about my future	I am <b>very</b> concerned about this when I think about my future	I am <b>extremely</b> concerned about this when I think about my future
a. <b>Daily functioning</b> , such as your ability to dress yourself, shower, make a phone call, use a computer, or other aspects of daily functioning	1	2	3	4	5
b. <b>Day-to-day variability</b> , such as the ups and downs of PD symptoms, having "on" and "off" periods throughout the day, or other day-to-day variabilities	1	2	3	4	5
c. <b>Loss of independence</b> , such as losing the ability to drive, to make your own decisions, or other ways you might lose independence	1	2	3	4	5
d. <b>Loss of mobility</b> , such as losing the ability to exercise, needing a walker or a wheelchair, or other loss of mobility	1	2	3	4	5
e. <b>Impact on housing</b> , such as needing to move in with family members, an assisted living, long-term care or	1	2	3	4	5

nursing facility, or other impacts on housing					
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## DISEASE PROGRESSION AND CARE NEEDS

*Simple matrix, single answer, multiple choice, required*

5. These statements focus on how **your Parkinson's disease may progress and what your care needs will be** in the future.

How concerned are you about each of the following when you think about your future with PD?

	I am <b>not at all</b> concerned about this when I think about my future	I am <b>a little</b> concerned about this when I think about my future	I am <b>somewhat</b> concerned about this when I think about my future	I am <b>very</b> concerned about this when I think about my future	I am <b>extremely</b> concerned about this when I think about my future
a. <b>Disease progression</b> , such as worsening of your PD symptoms, uncertainty about how the disease will progress, long term effectiveness of medications, or other concerns around disease progression	1	2	3	4	5
b. <b>Personal care</b> , such as needing assistance with oral care, bathing, dressing, or medications or other help with personal care.	1	2	3	4	5
c. <b>Quality of care</b> , such as availability of specialists, access to high quality clinical care, or other issues around quality of healthcare	1	2	3	4	5
d. <b>Individualized treatments</b> , such as availability of, and access to, treatment options tailored to your disease progression	1	2	3	4	5
e. <b>Invasive treatments</b> , such as needing deep brain stimulation, other surgery, or other treatments you consider to be invasive	1	2	3	4	5
f. <b>Death and dying</b> , such as the risk of dying, losing hope, having to make decisions about end of life care, or other issues around death and dying	1	2	3	4	5

## RELATIONSHIPS/SOCIAL IMPACT

*Simple matrix, single answer, multiple choice, required*

6. These statements focus on how Parkinson's disease may impact **your relationships and your social life** in the future.

How concerned are you about each of the following when you think about your future with PD?

	I am <b>not at all</b> concerned about this when I think about my future	I am <b>a little</b> concerned about this when I think about my future	I am <b>somewhat</b> concerned about this when I think about my future	I am <b>very</b> concerned about this when I think about my future	I am <b>extremely</b> concerned about this when I think about my future
a. <b>Impact on your family</b> , such as family or close friends, potentially being a burden on others, impact on your relationships, physical intimacy with your spouse or partner, or other impacts on your family	1	2	3	4	5
b. <b>Social impact</b> , such as your ability to maintain friendships, engage in hobbies and other activities, attend events, your ability to travel, or other social impacts	1	2	3	4	5
c. <b>Social stigma</b> , such feeling judged or pitied by others, or other social stigma	1	2	3	4	5

## FINANCIAL AND OTHER RESPONSIBILITIES

*Simple matrix, single answer, multiple choice, required*

7. These statements focus on how Parkinson's disease may impact **your financial and other responsibilities** in the future.

How concerned are you about each of the following when you think about your future with PD?

	I am <b>not at all</b> concerned about this when I think about my future	I am <b>a little</b> concerned about this when I think about my future	I am <b>somewhat</b> concerned about this when I think about my future	I am <b>very</b> concerned about this when I think about my future	I am <b>extremely</b> concerned about this when I think about my future
a. <b>Employment issues</b> , such as having to stop working/not being able to stop working on your own terms, having to change the nature of your work, losing productivity, having to inform your employer or colleagues of your diagnosis, or other employment issues	1	2	3	4	5

b. <b>Cost of PD care</b> , such as costs of: health insurance, medications, procedures, in-home care, long term care, or other PD-related costs	1	2	3	4	5
c. <b>Financial responsibilities</b> , such as being able to financially support yourself, losing the ability to financially support your spouse, children, or grandchildren, or other financial responsibilities	1	2	3	4	5
d. <b>Other responsibilities</b> , such as caring for family members, fulfilling other obligations, or other responsibilities	1	2	3	4	5

Display logic: For statement [a. Employment issues], if either [a.], [b.], or [c.] is chosen for “Which of the following best describes your current employment status?”

## SYMPTOMS

*Simple matrix, single answer, multiple choice, required*

8. These statements focus on how **various symptoms of Parkinson’s disease** may impact you in the future.

How concerned are you about each of the following symptoms when you think about your future with PD?

	I am <b>not at all</b> concerned about this when I think about my future	I am a <b>little</b> concerned about this when I think about my future	I am <b>somewhat</b> concerned about this when I think about my future	I am <b>very</b> concerned about this when I think about my future	I am <b>extremely</b> concerned about this when I think about my future
a. <b>Falling</b> , such as tripping, stumbling, loss of balance, risk of injuries from falls, or other issues around falling	1	2	3	4	5
b. <b>Other motor symptoms</b> , such as worsening tremors, freezing, muscle spasms, clenching, uncontrolled movements, trouble with handwriting or typing, or other motor symptoms	1	2	3	4	5
c. <b>Cognitive impairment</b> , such as loss of memory, difficulty finding words, confusion, dementia, multi-tasking, or other cognitive impairment issues	1	2	3	4	5
d. <b>Psychological/Mental health symptoms</b> , such as negative emotions, anxiety/worry,	1	2	3	4	5

sadness/depression, apathy, loneliness/isolation, hallucinations, compulsive behaviors, or other psychological symptoms					
e. <b>Sleep issues</b> , such as insomnia, fatigue, daytime sleepiness, acting out dreams, restlessness, injuring a bed-partner, or other sleep issues	1	2	3	4	5
f. <b>Autonomic/Other non-motor symptoms</b> , such as swallowing problems, frequent urination, constipation/GI issues, loss of smell, dizziness, sexual dysfunction, excessive sweating, or other non-motor symptoms	1	2	3	4	5

## TOP CONCERNS

9. You rated the items below to be of greatest concern to you as you think about your future with PD. Which of the following are you the most concerned about? *You may select up to three items, but if only one concern is listed, please select that concern to proceed.*

- a)
- b)
- c)

Question display logic: If scale point “extremely concerned” cumulative count is greater than 0 for matrices in questions 4-8

Answers display logic: Any statement that is answered with “extremely concerned” in matrices from questions 4-8

Skip logic: If selected answer count is greater than 0, skip to “Have you talked about any of these top concerns with the main healthcare provider who treats your PD?”

10. You rated the items below to be of greatest concern to you as you think about your future with PD. Which of the following are you the most concerned about? *You may select up to three items, but if only one concern is listed, please select that concern to proceed.*

- a)
- b)
- c)

Question display logic: If scale point “very concerned” cumulative count is greater than 0 in questions 4-8

& If previous question (Which of the following are you the most concerned about?) is NOT displayed.

Answers display logic: Any statement that is answered with “very concerned” in questions 4-8

*Multiple choice, single answer, required*

11. Have you talked about any of these top concerns with the main healthcare provider who treats your PD?

- a) Yes
- b) No
- c) Prefer not to answer

Display logic: If either Question 9 or Question 10 are displayed

*Multiple choice, multiple answer, required*

12. For this question, please think about all of the topics addressed in this survey, including quality of life, disease progression, relationships and social life, financial and other responsibilities, and PD symptoms. Who do you typically talk to about these issues? Please select all that apply.

- a) Spouse
- b) Other family members
- c) Friends
- d) Support groups/other people with PD
- e) Your main healthcare provider for PD
- f) Other healthcare providers
- g) A counselor or therapist
- h) Clergy or religious leaders
- i) I typically do not talk with anyone about these issues
- j) Other
- k) Prefer not to answer

*Multiple choice, single answer, required*

13. Do you feel the need to talk with someone about these issues?

- a) Yes
- b) No
- c) Prefer not to answer

Display logic: If (i. I typically do not talk with anyone about these issues) is selected for “For this question, please think about all of the topics addressed in this survey, including quality of life, disease progression, relationships and social life, financial and other responsibilities, and PD symptoms. Who do you typically talk to about these issues?”

*Multiple choice, single answer, required*

14. This survey used the word “concerns” to ask about how you are feeling about your future. However, there are many different emotions that people experience when thinking about the future. Which word best describes the way you feel as you think about your future with Parkinson’s Disease?

- a) Concern
- b) Fear

- c) Worry
- d) Anxiety
- e) Uncertainty
- f) Other
- g) Prefer not to answer

**End of Survey thank you:**

Thank you for your participation in this survey. Your answers will help us learn more about how people truly feel about their future with Parkinson's disease.

It is possible that this survey may have brought up difficult feelings for you. If so, please return to the email invitation you received about this survey where you will find a link to resources that you may find helpful.

**Please click on the next arrow below (>>) to submit your responses and be redirected to the Fox Insight website.**

**End of Survey thank you 2:** Thank you for participating in Fox Insight. This survey is currently only collecting responses from people with a diagnosis of Parkinson's disease. We appreciate your interest in sharing your experiences. **Please click on the next arrow below (>>) to submit your responses and be redirected to the Fox Insight website.**