

Impact of Thinking, Mood, and Motor Symptoms

The Stigma section of this survey (Q13, Q20 and Q22) includes an adaptation of the “Quality of Life in Neurological Disorders (Neuro-QoL) Item bank v1.0 - Stigma”.

Items NQSTG-01, 02, 04, 07 and 15 from the “Neuro-QoL Item bank v1.0 – Stigma” were modified as follows:

1. The verb tense was changed from the past to the present tense to reflect the ongoing nature of Parkinson’s disease.
2. Questions were reworded to refer to specific symptoms of interest (cognitive, mood and motor) rather than to the illness in general.
3. The response options were changed and therefore *the original scoring no longer applies*. Response options in the present version include: Never/Sometimes/Always/Not sure/Prefer not to answer.

Any presentation or publication of results relying on this survey should include a description of the modifications, as detailed above, and should be cited as follows:

Gershon, R. C., Lai, J. S., Bode, R., Choi, S., Moy, C., Bleck, T., Miller, D., Peterman, A., & Cella, D. (2012). Neuro-QOL: Quality of life item banks for adults with neurological disorders: item development and calibrations based upon clinical and general population testing. *Quality of Life Research : An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation*, 21(3), 475–486. <https://doi.org/10.1007/s11136-011-9958-8>

Rao, D., Choi, S.W., Victorson, D., Bode, R., Peterman, A., Heinemann, A., & Cella, D. (2009). Measuring Stigma across Neurological Conditions: The Development of the Stigma Scale for Chronic Illness (SSCI). *Quality of Life Research*, 18(5), 585-595. <http://dx.doi.org/10.1007/s11136-009-9475-1>

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Impact of Thinking, Mood and Motor Symptoms

[INTRODUCTION]

Thank you for taking part in this survey. The purpose of this survey is to better understand your experience with Parkinson's disease (PD), what you know about it, and what you want to know about it. This survey will ask you about your Parkinson's symptoms and how you feel the disease affects your thinking and mood. You will also be asked about what you know about Parkinson's disease, how you learned it, and what you feel others know about it.

Throughout this survey, we will be making references to your "**health care team.**" Your **health care team** can include any of the health professionals that assist in the management of your Parkinson's disease, such as a neurologist, nurses, occupational therapist, social workers, primary care physicians, etc.

Multiple choice, single answer, required

1. Have you been diagnosed with Parkinson's disease?
 - a. Yes
 - b. No

Skip Logic: If (b. No) is selected, skip to End of Survey thank you 1.

Multiple choice, multiple answer, required

2. My Parkinson's disease is currently being treated by a...
 - a. Movement Disorder Specialist
 - b. General Neurologist
 - c. Family Doctor/Primary Care Doctor
 - d. Nurse Practitioner/Physician Assistant
 - e. Other

Multiple choice, multiple answer, required

3. Which of the following **movement and bodily function** Parkinson's disease symptoms do you currently experience? Please select all the apply.
 - a. Slowness of movement
 - b. Speech difficulty (low voice, slurring, mumbling)
 - c. Tremors
 - d. Loss of dexterity (e.g., difficulty with things like buttons, zippers, brushing teeth)
 - e. Imbalance or tendency to fall
 - f. Walking problems (e.g., slow walking, freezing)
 - g. Visual hallucinations (e.g., seeing things that are not really there)
 - h. Reduced sense of smell
 - i. Swallowing difficulty
 - j. Bodily pain or discomfort (e.g., generalized, or of the joints)
 - k. Urinary problems (e.g., increased frequency, loss of bladder control)
 - l. Constipation
 - m. Acting out dreams (e.g., punching, kicking or shouting during sleep)
 - n. Difficulty sleeping or insomnia
 - o. Dyskinesias (e.g., unintentional movements related to the Parkinson's medications)
 - p. None of the above

- q. Not sure
- r. Prefer not to answer

Dependent matrix, single answer, required

4. In the prior question, you selected the following Parkinson’s symptoms because you experience them currently. Please rate how you feel these symptoms impact your quality of life.

Impact:	a. Not at all (0)	b. A little (1)	c. Moderately (2)	d. Quite a bit (3)	e. Extremely (4)
[Symptom]					

Display Logic: For any symptom selected for “Which of the following movement and bodily function Parkinson’s disease symptoms do you currently experience? Please select all the apply.”, corresponding item will be displayed in this matrix.

Multiple choice, multiple answer, required

5. Which of the following **thinking and feeling** Parkinson’s disease symptoms do you currently experience? Please select all that apply.
- a. Difficulty with decisions or planning
 - b. Slowing of mental or information processing
 - c. Memory problems
 - d. Difficulty with expressing your thoughts (e.g., word-finding difficulties)
 - e. Difficulty concentrating
 - f. Depression or sadness
 - g. Anxiety or excessive worrying
 - h. Physical fatigue (e.g., exhaustion or tiredness of the body)
 - i. Mental fatigue (e.g., feeling weary or exhausted during a mental task)
 - j. Difficulty controlling emotions or behaviors
 - k. Feeling lightheaded or dizzy
 - l. Apathy (e.g., reduced motivation, needing more of a push)
 - m. Difficulty with multi-tasking
 - n. Feeling of being alone or being isolated
 - o. None of the above
 - p. Not sure
 - q. Prefer not to answer

Dependent matrix, single answer, required

6. In the prior question, you selected the following Parkinson’s symptoms because you experience them currently. Please rate how you feel these symptoms impact your quality of life.

Impact:	a. Not at all (0)	b. A little (1)	c. Moderately (2)	d. Quite a bit (3)	e. Extremely (4)
[Symptom]					

Display Logic: For any symptom selected for “Which of the following thinking and feeling Parkinson’s disease symptoms do you currently experience? Please select all the apply.”, corresponding item will be displayed in this matrix.

Cognition

The following questions are aimed at understanding if, and how, Parkinson’s disease affects your **thinking**.

Some examples of **thinking problems** might include:

- **Memory:** such as remembering what someone recently told you, familiar names, or upcoming events
- **Concentration:** such as reading an article or book, or watching a television show or movie
- **Organization:** such as paying bills, managing medications, or organizing and completing a shopping list
- **Making decisions and solving problems**
- **Orientation and spatial ability:** such as driving or finding one’s way around an unfamiliar location.
- **Understanding language:** such as making sense of conversations or finding words when talking

Multiple choice, single answer, required

7. Have you noticed that you are having more **problems with thinking**, that is a change from your normal abilities?
 - a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Multiple choice, multiple answer, required

8. What do you **MOST** believe are the reasons for your **thinking changes**? Please select all that apply.
 - a. PD
 - b. Aging
 - c. Stress and coping with disease
 - d. Stress related to other life events
 - e. Other neurological illness
 - f. Other
 - g. Not sure
 - h. Prefer not to answer

Display Logic: If (a. Yes) is selected for “Have you noticed that you are having more problems with thinking, that is a change from your normal abilities?”

Multiple choice, single answer, required

9. Has your health care team prescribed medications for your **thinking symptoms**?

- a. Yes
- b. No
- c. Not sure
- d. Prefer not to answer

Display Logic: If (a. Yes) is selected for “Have you noticed that you are having more problems with thinking, that is a change from your normal abilities?”

Multiple choice, single answer, required

10. **When** did you first learn that **thinking changes** are part of the symptoms of PD?
- a. I did not know anything about thinking changes in PD before filling out this survey
 - b. Before PD diagnosis (I already knew about PD and its symptoms before I received my diagnosis)
 - c. At the time of PD diagnosis; it was discussed by the healthcare team
 - d. After my diagnosis of PD because I started to learn about the disease
 - e. Only once I started to experience thinking changes myself
 - f. Other
 - g. Not sure
 - h. Prefer not to answer

Display Logic: If (a. Yes) is selected for “Have you noticed that you are having more problems with thinking, that is a change from your normal abilities?”

Multiple choice, multiple answer, required

11. **How** did you first learn that **thinking changes** are part of the symptoms of PD? Please select all that apply.
- a. By doing this survey
 - b. My physician
 - c. Other health care worker (e.g., occupational therapist, nurse)
 - d. Printed materials from clinic
 - e. Information provided by foundations (e.g., webinar, printed materials)
 - f. Support groups
 - g. Social media
 - h. Friends/family doing research
 - i. Other
 - j. Not sure
 - k. Prefer not to answer

Display Logic: If (a. Yes) is selected for “Have you noticed that you are having more problems with thinking, that is a change from your normal abilities?”

Multiple choice, single answer, required

12. Which **ONE** of the following items was the **MOST** helpful in learning that **thinking changes** are part of the symptoms of PD? Please select the best option.
- a. [selected learning mechanisms from Q11]

Answer Option Logic: For any ‘learning mechanism’ selected for “How did you first learn about the possibility of thinking changes associated with PD?”, corresponding item will be displayed in this question.

Question Display Logic: If (j. Not sure) or (k. Prefer not to answer) is NOT selected AND if more than one answer choice is selected for “How did you first learn about the possibility of thinking changes associated with PD?”

13. In this section, we want to know how you think that Parkinson’s disease and its associated **symptoms affect the way that other people see you**. You told us earlier that you have noticed more **problems with thinking**, that is a change from your normal abilities. Please consider these symptoms affecting your thinking and tell us how often you experience the following:

Multiple choice matrix, single answer, required

Because of my thinking symptoms...	a. Never (1)	b. Sometimes (2)	c. Always (3)	d. Not sure (4)	e. Prefer not to answer (5)
Some people seem uncomfortable with me.					
Some people are avoiding me.					
I feel embarrassed in social situations.					
I feel left out to things.					
I worry that I am a burden to others.					

Display Logic: If (a. Yes) is selected for “Have you noticed that you are having more problems with thinking, that is a change from your normal abilities?”

Mood

The following questions are aimed at understanding if, and how, you have experienced **mood changes** (whether related or unrelated to Parkinson’s disease).

We are using the term ‘**mood**’ to refer to all emotional states, which can include happiness, sadness, hopelessness, depression, anger, fear, excessive worry, anxiety, irritability, loss of motivation, paranoia, difficulty controlling urges, compulsions, obsessions, etc.

People with Parkinson’s disease might experience mood changes for a variety of reasons. Some people notice very little or no changes at all, while others notice more significant changes. These changes might be related or unrelated to Parkinson’s disease.

Multiple choice, single answer, required

14. Have you experienced **changes to your mood** since your diagnosis with Parkinson’s disease?
- Yes
 - No
 - Not sure

- d. Prefer not to answer

Multiple choice, multiple answer, required

15. What do you **MOST** believe are the reasons for the **change to your mood**? Please select all that apply.
- a. PD
 - b. Aging
 - c. Stress and coping with disease
 - d. Stress related to other life events
 - e. Pre-existing psychiatric condition (e.g., major depression, bipolar disorder, schizophrenia, etc.)
 - f. Other medical condition
 - g. Not sure
 - h. Prefer not to answer

Display Logic: If (a. Yes) is selected for “Have you experienced changes to your mood since your diagnosis with Parkinson’s disease?”

Multiple choice, single answer, required

16. Has your health care team prescribed any medications for your **mood symptoms**?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Display Logic: If (a. Yes) is selected for “Have you experienced changes to your mood since your diagnosis with Parkinson’s disease?”

Multiple choice, single answer, required

17. **When** did you first learn that **mood changes** are part of the symptoms of Parkinson’s disease?
- a. I did not know anything about mood changes in PD before filling out this survey
 - b. Before PD diagnosis (I already knew about PD and its symptoms before I received my diagnosis)
 - c. At time of PD diagnosis; it was discussed by the health care team
 - d. After my diagnosis of PD because I started to learn about the disease
 - e. Only once I started to experience mood changes myself
 - f. Other
 - g. Not sure
 - h. Prefer not to answer

Display Logic: If (a. Yes) is selected for “Have you experienced changes to your mood since your diagnosis with Parkinson’s disease?”

Multiple choice, multiple answer, required

18. **How** did you first learn that **mood changes** are part of the symptoms of Parkinson’s disease? Please select all that apply.
- a. By doing this survey
 - b. My physician
 - c. Other health care worker (e.g., occupational therapist, nurse)
 - d. Printed materials from clinic
 - e. Information provided by foundations (e.g., webinar, printed materials)

- f. Support groups
- g. Social media
- h. Friends/family doing research
- i. Other
- j. Not sure
- k. Prefer not to answer

Display Logic: If (a. I did not know anything about mood changes in PD before filling out this survey), (g. Not sure) or (h. Prefer not to answer) is NOT selected for “When did you first learn that mood changes are part of the symptoms of Parkinson’s disease?”

Multiple choice, single answer, required

19. Which **ONE** of the following items was the **MOST** helpful in learning that **mood changes** are part of the symptoms of Parkinson’s disease? Please select the best option.

a. [selected learning mechanisms from Q18]

Answer Option Logic: For any ‘learning mechanism’ selected for “How did you first learn that mood changes are part of the symptoms of Parkinson’s disease?”, corresponding item will be displayed in this question.

Question Display Logic: If (j. Not sure) or (k. Prefer not to answer) is NOT selected for “How did you first learn that mood changes are part of the symptoms of Parkinson’s disease?”.

20. In this section, we want to know how you think that Parkinson’s disease and its associated symptoms **affect the way that other people see you**. You told us earlier that you have **changes to your mood**. Please consider these mood symptoms and tell us how often you experience the following:

Multiple choice matrix, single answer, required

Because of my mood symptoms...	a. Never (1)	b. Sometimes (2)	c. Always (3)	d. Not sure (4)	e. Prefer not to answer (5)
Some people seem uncomfortable with me.					
Some people are avoiding me.					
I feel embarrassed in social situations.					
I feel left out to things.					
I worry that I am a burden to others.					

Display Logic: If (a. Yes) is selected for “Have you experienced changes to your mood since your diagnosis with Parkinson’s disease?”

Motor

In this section, we are asking about the **motor symptoms** of Parkinson’s disease, which can include tremor, stiffness, slowness, difficulty walking, poor balance, falls, loss of dexterity, difficulty with activities such as dressing, cooking, or eating, etc.

Multiple choice, single answer, required

21. Have you experienced **motor symptoms** since your diagnosis with Parkinson’s disease?

- a. Yes
- b. No
- c. Not sure
- d. Prefer not to answer

22. In this section, we want to know how you think that Parkinson’s disease and its associated symptoms **affect the way that other people see you**. You told us earlier that you experienced **motor symptoms** since your diagnosis of Parkinson’s disease. Please consider your motor symptoms and tell us how often you experience the following:

Multiple choice matrix, single answer, required

Because of my <u>motor symptoms</u>...	a. Never (1)	b. Sometimes (2)	c. Always (3)	d. Not sure (4)	e. Prefer not to answer (5)
Some people seem uncomfortable with me.					
Some people are avoiding me.					
I feel embarrassed in social situations.					
I feel left out to things.					
I worry that I am a burden to others.					

Display Logic: If (a. Yes) is selected for “Have you experienced motor symptoms since your diagnosis with Parkinson’s disease?”

Your expectations about the symptoms of Parkinson’s disease

In this section, we are interested in finding out about how you **expected** that Parkinson’s disease **would** affect you (e.g., based on what your healthcare team had told you, what you have read about PD, or how you have seen PD depicted in the media/culture), compared to how it **is** affecting you.

Multiple choice, single answer, required

23. How does your **experience of changes to your thinking** (or absence of any changes) since your diagnosis of Parkinson’s disease **compare** to the thinking changes you **expected** would occur as a result of having Parkinson’s disease?

- a. This is exactly what I expected

- b. This is not as bad as I thought it would be
- c. I was expecting some changes to my thinking, but this is worse than I thought it would be
- d. I didn't know about the possibility of developing changes to my thinking
- e. Other
- f. Not sure
- g. Prefer not to answer

Multiple choice, single answer, required

24. How does your **experience of mood symptoms** (or absence of mood symptoms) since your diagnosis of Parkinson's disease **compare** to the mood symptoms you **expected** would occur as a result of having Parkinson's disease?
- a. This is exactly what I expected
 - b. This is not as bad as I thought it would be
 - c. I was expecting some changes to my mood, but this is worse than I thought it would be
 - d. I didn't know about the possibility of developing changes to my mood
 - e. Other
 - f. Not sure
 - g. Prefer not to answer

What you know about Parkinson's disease

In this section, we are interested in finding out what you know about Parkinson's disease. **The point here is not to test you, but rather to get an idea of how well health care teams inform patients about their condition.** Later we will be asking what you *want to know about PD*.

Sliding scale, single answer, required

25. **Dementia**: As people progress with PD, what percentage of people do you think will eventually develop **dementia** due to Parkinson's disease?

Dementia refers to changes to thinking that are severe enough to cause a partial or total loss of independence.

If you believe few people with PD develop dementia, choose a low number on the slider below. Choose a high number if you believe more people with PD eventually develop dementia.

For example:

0% = No one with PD develops dementia

100% = Everyone with PD develops dementia eventually

Select a percentage by sliding the circle icon

0 10 20 30 40 50 60 70 80 90 100

Sliding scale, single answer, required

26. **Thinking changes:** What percentage of people do you think will eventually develop **any degree of changes to their thinking** due to Parkinson's disease?

We are referring to any changes in memory, concentration, organization, orientation, or any other changes to thinking, whether mild or severe, that are sufficient to be noted by the individual or by their loved ones. These changes could be so mild that they don't affect everyday life, to so severe that they lead to loss of independence and dementia. (The percentage you provide here should be at least as high as the number you entered in the last question).

If you believe few people with PD develop thinking changes, choose a low number on the slider below. Choose a high number if you believe more people with PD develop thinking changes.

For example:

0% = No one with PD develops any degree of thinking changes

100% = Everyone with PD develops some degree of thinking changes

Select a percentage by sliding the circle icon

0 10 20 30 40 50 60 70 80 90 100

Multiple choice, multiple answer, required

27. The treatment for **thinking changes** in Parkinson's diseases involves:

Please select all that apply.

- a. Medication to cure the thinking changes, i.e., to permanently reverse the thinking changes
- b. Medication to alleviate the symptoms of thinking changes, i.e., to reduce their severity
- c. No medications exist, but therapies that do not involve medications (e.g., occupational therapy) can help cope with the changes
- d. Nothing at all can be done for the thinking changes in PD
- e. Other
- f. Not sure
- g. Prefer not to answer

Sliding scale, single answer, required

28. **Mood symptoms:** As people progress with PD, what percentage of people will, at some point, experience **changes to their mood** due to Parkinson's disease?

Mood symptoms include depression, anxiety, excessive worrying, loss of motivation, paranoia, etc.

If you believe few people will experience mood symptoms, choose a low number on the slider below. Choose a high number if you believe more people with PD will experience mood symptoms.

For example:

0% = No one with PD develops any degree of mood symptoms

100% = Everyone with PD develops some degree of mood symptoms

Select a percentage by sliding the circle icon

Multiple choice, multiple answer, required

29. The treatment of mood symptoms in Parkinson's disease involves:

Please select all that apply.

- a. Medication to cure the mood symptoms, i.e., to permanently reverse the mood symptoms
- b. Medication to alleviate the mood symptoms
- c. No medications exist, but therapy that does not involve medications (e.g., talk therapy) can help cope with or reduce the symptoms
- d. Nothing at all can be done for the mood symptoms in PD
- e. Other
- f. Not sure
- g. Prefer not to answer

About your interaction with the health care team

In this section, we are interested in finding out how much information you receive from your **health care team** and whether you are satisfied with your interactions with your health care team.

Your **health care team** can include any of the health professionals that assist in the management of your Parkinson's disease, such as a neurologist, nurses, occupational therapist, social workers, primary care physicians, etc.

Multiple choice, single answer, required

30. How often do you discuss whether you've experienced **changes to your thinking** in your visits?

- a. Each visit
- b. Only when I bring it up
- c. My health care team occasionally brings it up
- d. I have never discussed this with my health care team
- e. Other
- f. Not sure
- g. Prefer not to answer

Multiple choice, single answer, required

31. Do you think the time you spend with your health care team discussing **your thinking** is sufficient?

- a. Yes
- b. No
- c. Not sure
- d. Prefer not to answer

Multiple choice, single answer, required

32. How often do you discuss your **mood symptoms** in your visits?

- a. Each visit
- b. Only when I bring it up
- c. My health care team occasionally brings it up
- d. I have never discussed this with my health care team

- e. Other
- f. Not sure
- g. Prefer not to answer

Multiple choice, single answer, required

33. Do you think the time you spend with your health care team discussing **mood symptoms** is sufficient?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Multiple choice, single answer, required

34. Do you have a care partner who attends medical appointments with you some or all of the time?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Multiple choice, single answer, required

35. Do you find that your care partner is sufficiently involved in the conversations with your health care team?
- a. Yes
 - b. No, because they can't attend often enough
 - c. No, because the health care team does not include them enough in the discussion
 - d. No, because they prefer not to be involved in the discussions
 - e. No, because I prefer them not to be involved in the discussions
 - f. Other
 - g. Not sure
 - h. Prefer not to answer

Display Logic: If (a. Yes) is selected for "Do you have a care partner who attends medical appointments with you some or all of the time?"

Multiple choice, multiple answer, required

36. Since my time of PD diagnosis, I view the **thinking and mood symptoms** that I experience as:
Please choose all that apply.
- a. A part of life
 - b. Related to Parkinson's disease
 - c. Entirely under my control and therefore I would rather not discuss them with the health care team
 - d. Without effective treatment, therefore I would rather not discuss them
 - e. Less important than my motor symptoms
 - f. More important than my motor symptoms
 - g. Embarrassing
 - h. Other
 - i. None of the above, I do not experience thinking and mood symptoms
 - j. Not sure
 - k. Prefer not to answer

Understanding what you would like to know

In this section, we are interested in finding out how you **would ideally like** the different aspects of Parkinson's disease to be discussed with you.

Multiple choice, multiple answer, required

37. What is the **value** to you of discussing **thinking and mood symptoms** with your healthcare team?

Please choose all that apply.

- a. It is helpful to talk about the symptoms and have them validated
- b. It is helpful to talk about the symptoms so that they can be treated
- c. It is helpful to talk about these symptoms in front of my care partner so that they have a better understanding of what I'm going through
- d. It is helpful for the healthcare team to hear my care partner's perspective on these issues
- e. It is not useful; I would prefer to focus on other symptoms of Parkinson's disease
- f. It is not useful; I don't experience these symptoms
- g. Other
- h. Not sure
- i. Prefer not to answer

Multiple choice, single answer, required

38. Ideally, would you have wanted to be told about the **possibility** of developing **thinking and mood symptoms** as part of Parkinson's disease **at the time of your diagnosis**?

- a. Yes, I think it's important to be informed about the possibility of developing these symptoms, even if I was not experiencing them yet
- b. No, I would have preferred to wait until I develop the symptoms before being told about their link to Parkinson's disease
- c. Other
- d. Not sure
- e. Prefer not to answer

End of Survey thank you 1:

Thank you for participating in Fox Insight. This survey is currently only collecting responses from people who have been diagnosed with 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.**

End of Survey thank you 2:

Thank you for taking part in this survey. Your answers will help us learn more about your experience as a person living with Parkinson's disease. **Please click on the next arrow below (>>) to submit your responses and be redirected to the Fox Insight website.**