

Covid-19 Experience in the PD Community – Part 2

The COVID-19 pandemic has changed life for people around the world. There is no evidence that people with Parkinson's are at higher risk of getting COVID-19. But we have more to learn on how the pandemic has impacted people with the disease and their care partners.

You can help by sharing your experience. This survey needs people with and without Parkinson's disease. This information can help us learn more about the effects of COVID-19 and the pandemic. That knowledge could help improve care and quality of life for people with Parkinson's.

This is the second Fox Insight survey on the COVID-19 pandemic. You may take this survey if you completed the first survey or not.

Multiple choice, single answer, required

1. Have you been diagnosed with Parkinson's disease?
 - a. Yes, I have been diagnosed with Parkinson's disease
 - b. No, I have not been diagnosed with Parkinson's disease

Part 1: COVID-19 Vaccine

These first questions ask about your experience with a COVID-19 vaccine.

Multiple choice, single answer, required

2. Have you received a COVID-19 vaccine?
 - a. Yes, one dose
 - b. Yes, two doses
 - c. No
 - d. Not sure
 - e. Prefer not to answer

Text box, numerical limited to 1-12 for Month (MM) and 2020-2025 for Year (YYYY), required

3. When did you receive your first COVID-19 vaccine dose?
If you are not sure, please make your best guess.

Month (MM): _____ Year (YYYY): _____

Display Logic: If (a. Yes, one dose) OR (b. Yes, two doses) is selected for "Have you received a COVID-19 vaccine?"

Multiple choice, single answer, required

4. Which COVID-19 vaccine did you receive for your first dose?
 - a. Pfizer-BioNTech
 - b. Moderna
 - c. Johnson & Johnson's Janssen
 - d. AstraZeneca/Oxford
 - e. Novavax
 - f. Other
 - g. Not sure

h. Prefer not to answer

Display logic: If (a. Yes, one dose) OR (b. Yes, two doses) is selected for “Have you received a COVID-19 vaccine?”

Text box, numerical limited to 1-12 for Month (MM) and 2020-2025 for Year (YYYY), required

5. When did you receive your second COVID-19 vaccine dose? If you are not sure, please make your best guess.

Month (MM): _____ Year (YYYY): _____

Display Logic: If (b. Yes, two doses) is selected for “Have you received a COVID-19 vaccine?”

Multiple choice, single answer, required

6. Which COVID-19 vaccine did you receive for your second dose?

- i. Pfizer-BioNTech
- j. Moderna
- k. Johnson & Johnson’s Janssen
- l. AstraZeneca/Oxford
- m. Novavax
- n. Other
- o. Not sure
- p. Prefer not to answer

Display logic: If (b. Yes, two doses) is selected for “Have you received a COVID-19 vaccine?”

Multiple choice, single answer, required

7. How likely are you to get the COVID-19 vaccine in the future?

- a. Not at all likely
- b. Not likely
- c. Neutral
- d. Somewhat likely
- e. Very Likely

Display Logic: If (b. No) is selected for “Have you received at least one dose of a COVID-19 vaccine?”

Multiple choice, multiple answer, required

8. Did you experience any of the following symptoms in the days immediately after your COVID-19 vaccine? Please select all that apply.

- a. Sore arm
- b. Fever above 100 F/37.8 C
- c. Chills
- d. Other
- e. None of the above

Display Logic: If (a. Yes, one dose) OR (b. Yes, two doses) is selected for “Have you received at least one dose of a COVID-19 vaccine?”

Multiple choice, single answer, required

9. How severe were the symptoms you experienced in the days immediately after your COVID-19 vaccine?

- a. Mild – symptoms did not interfere with daily activities
- b. Moderate – symptoms limited some daily activities

- c. Severe – symptoms prevented most or all daily activities (i.e., bedbound)

Display Logic: If (a.) through (d.) is selected for “Did you experience any of the following symptoms in the days immediately after your COVID-19 vaccine?”

Multiple choice, single answer, required

10. Did any of your Parkinson’s disease related symptoms **worsen** in the days immediately after your COVID-19 vaccine?
- Yes
 - No
 - Not sure
 - Prefer not to answer

Display Logic: If (a. Yes, I have been diagnosed with Parkinson’s disease) is selected for “Have you been diagnosed with Parkinson’s disease?” AND (a. Yes, one dose) OR (b. Yes, two doses) is selected for “Have you received at least one dose of a COVID-19 vaccine?”

Multiple choice, multiple answer, required

11. Which Parkinson’s disease related *movement* symptoms **worsened** in the days immediately after your COVID-19 vaccine?

Please select all that apply.

- Problems with walking
- Problems with balance
- Problems with falling
- Shaking or tremor
- Slow movements
- Stiffness
- Problems swallowing pills
- Problems eating meals
- OFF time - period during which PD medication(s) were not working as well
- Dyskinesia - uncontrolled, involuntary movements such as fidgeting, writhing, wriggling, head bobbing, or body swaying
- None of the above

Display Logic: If (a. Yes) is selected for “Did any of your Parkinson’s disease related symptoms **worsen** in the days immediately after your COVID-19 vaccine?”

Multiple choice, multiple answer, required

12. Which Parkinson’s disease related *thinking and feeling* symptoms **worsened** in the days immediately after your COVID-19 vaccine?

Please select all that apply.

- Difficulty sleeping- trouble getting to sleep or staying asleep through the night (insomnia)
- Trouble staying awake during the daytime
- Acting out your dreams while asleep - punching, flailing your arms in the air, making running movements, etc.
- Trouble thinking clearly, remembering things, and being attentive
- Memory loss- trouble remembering things
- Confusion - not knowing where you are, the date/time, who familiar people are

- g. Hallucinations - hearing, seeing, feeling, tasting, or smelling something that wasn't really there
- h. Anxiety - feeling nervous, worried, or tense more than usual
- i. Depression - periods of sadness, hopelessness, emptiness, or loss of enjoyment
- j. Fatigue - physical and mental state of having extremely low energy
- k. Apathy - decreased motivation, initiative, or spontaneity
- l. None of the above

Display Logic: If (a. Yes) is selected for "Did any of your Parkinson's disease related symptoms **worsen** in the days immediately after your COVID-19 vaccine?"

Multiple choice, multiple answer, required

13. Which Parkinson's disease related *bodily function* symptoms **worsened** in the days immediately after your COVID-19 vaccine?

Please select all that apply.

- a. Urinary problems - feeling an urgent need to urinate, a need to urinate too often, or having urine accidents
- b. Low blood pressure - feeling light-headed when standing up or sitting up after lying down, sitting, or squatting
- c. Constipation - fewer than three bowel movements a week or having to strain to pass a stool
- d. None of the above

Display Logic: If (a. Yes) is selected for "Did any of your Parkinson's disease related symptoms **worsen** in the days immediately after your COVID-19 vaccine?"

Multiple choice, single answer, required

14. How long did the worsening of your Parkinson's disease symptoms last?

- a. Less than 1 day
- b. 1 day
- c. 2 days
- d. 3 days
- e. More than 3 days

Display Logic: If (a. Yes, I have been diagnosed with Parkinson's disease) is selected for "Have you been diagnosed with Parkinson's disease?" AND (a. Yes, one dose) OR (b. Yes, two doses) is selected for "Have you received at least one dose of a COVID-19 vaccine?" AND (a. Yes) is selected for "Did any of your Parkinson's disease related symptoms **worsen** in the days immediately after your COVID-19 vaccine?"

Part 2: COVID-19 Experience

These questions ask about your history and experience with COVID-19.

Multiple choice, single answer, required

15. Have you **ever** been diagnosed with COVID-19 by a medical professional?
- I have been diagnosed with COVID-19
 - I have been told I may have COVID-19
 - I have not been diagnosed with COVID-19
 - Not sure
 - Prefer not to answer

Skip Logic: If (c), (d), or (e) is selected, skip to “Please tell us a little about where you currently live:”

Text box, numerical limited to 1-12 for Month (MM) and 2019-2025 for Year (YYYY), required

16. When were you diagnosed or told you may have COVID-19 by a medical professional?
If you are not sure, please make your best guess.

Month (MM): _____ Year (YYYY): _____

Display Logic: If (a. I have been diagnosed with COVID-19) or (b. I have been told I may have COVID-19) is selected for “Have you been diagnosed with COVID-19 by a medical professional?”

Multiple choice, single answer, required

17. When you were diagnosed with COVID-19 or told you may have COVID-19, were you also tested for COVID-19?
- Yes
 - No
 - Not sure
 - Prefer not to answer

Display Logic: If (a. I have been diagnosed with COVID-19) or (b. I have been told I may have COVID-19) is selected for “Have you been diagnosed with COVID-19 by a medical professional?”

Multiple choice, single answer, required

18. What was the COVID-19 test result?
- According to the result, I had COVID-19
 - According to the result, I did not have COVID-19
 - The test result could not be interpreted by my doctor
 - The test results are not available yet
 - I don't know the test results
 - Prefer not to answer

Display Logic: If (a. Yes) is selected for “When you were diagnosed with COVID-19, were you also tested for COVID-19?”

Multiple choice, single answer, required

19. Have you ever received a positive COVID-19 test result while not showing symptoms (asymptomatic COVID-19 infection)?
- Yes
 - No
 - Not sure
 - Prefer not to answer

Display Logic: If (b. According to the result, I did not have COVID-19) is selected for “What was the COVID-19 test result?”

Multiple choice, single answer, required

20. Prior to your COVID-19 diagnosis or your suspected diagnosis, did you have any problems with your sense of smell?
- Yes
 - No
 - Not sure
 - Prefer not to answer

Display Logic: If (a. I have been diagnosed with COVID-19) or (b. I have been told I may have COVID-19) is selected for “Have you been diagnosed with COVID-19 by a medical professional? “OR (a. Yes) is selected for “Have you ever received a positive COVID-19 test result while not showing symptoms (asymptomatic COVID-19 infection)?

Multiple choice, single answer, required

21. Did you experience **worsening** of your sense of smell when you had COVID-19?
- Yes
 - No
 - Not sure
 - Prefer not to answer

Display Logic: If (a. Yes) is selected for “Prior to your COVID-19 diagnosis, did you have any problems with your sense of smell?”

Multiple choice, single answer, required

22. Did you experience problems with your sense of smell when you had COVID-19?
- Yes
 - No
 - Not sure
 - Prefer not to answer

Display Logic: If (b. No) or (c. Not sure) is selected for “Prior to your COVID-19 diagnosis, did you have any problems with your sense of smell?”

Multiple choice, single answer, required

23. Has your sense of smell improved since you have recovered from COVID-19?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Display Logic: If (a. Yes) is selected for “Did you experience **worsening** of sense of sense of smell when you had COVID-19?” OR (a. Yes) is selected for “Did you experience problems with your sense of smell when you had COVID-19?”

Multiple choice, single answer, required

24. How long did it take for your sense of smell to improve after your COVID-19 diagnosis?
- a. Less than or equal to 1 month
 - b. More than 1 but less than 2 months
 - c. More than 2 but less than 3 months
 - d. More than 3 but less than 6 months
 - e. More than 6 months

Display Logic: If (a. Yes) is selected for “Has your sense of smell improved since you have recovered from COVID-19?”

Multiple choice, single answer, required

25. Prior to your COVID-19 diagnosis or your suspected diagnosis, did you have any problems with your sense of taste or ability to sense food flavor?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Display Logic: If (a. I have been diagnosed with COVID-19) or (b. I have been told I may have COVID-19) is selected for “Have you been diagnosed with COVID-19 by a medical professional?” OR (a. Yes) is selected for “Have you ever received a positive COVID-19 test result while not showing symptoms (asymptomatic COVID-19 infection)?”

Multiple choice, single answer, required

26. Did you experience **worsening** of your sense of taste or ability to sense food flavor when you had COVID-19?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Display Logic: If (a. Yes) is selected for “Prior to your COVID-19 diagnosis, did you have any problems with your sense of taste or ability to sense food flavor?”

Multiple choice, single answer, required

27. Did you experience problems with your sense of taste or ability to sense food flavor when you had COVID-19?
- Yes
 - No
 - Not sure
 - Prefer not to answer

Display Logic: If (b. No) or (c. Not sure) is selected for “Prior to your COVID-19 diagnosis, did you have any problems with your sense of taste or ability to sense food flavor?”

Multiple choice, single answer, required

28. Has your sense of taste or ability to sense food flavor improved since you have recovered from COVID-19?
- Yes
 - No
 - Not sure
 - Prefer not to answer

Display Logic: If (a. Yes) is selected for “Did you experience **worsening** of sense of taste or ability to sense food flavor when you had COVID-19?” OR (a. Yes) is selected for “Did you experience problems with your sense of taste or ability to sense food flavor when you had COVID-19?”

Multiple choice, single answer, required

29. How long did it take for your sense of taste or ability to sense food flavor to improve after your COVID diagnosis?
- Less than or equal to 1 month
 - More than 1 but less than 2 months
 - More than 2 but less than 3 months
 - More than 3 but less than 6 months
 - More than 6 months

Display Logic: If (a. Yes) is selected for “Has your sense of taste or ability to sense food flavor improved since you have recovered from COVID-19?”

Multiple choice, multiple answer, required

30. Did you experience any of the following symptoms when you had COVID-19?

Please select all that apply.

Whole Body:

- Fever above 100 F/37.8 C
- Chills
- Headache
- Excessive tiredness or fatigue
- Excessive sleepiness such as falling asleep during the day
- Difficulty sleeping- trouble getting to sleep or staying asleep through the night (insomnia)
- Red, itchy, painful eyes (conjunctivitis or pink eye)
- Skin Rash
- Sore throat
- Nasal congestion or runny nose

Lungs and Heart:

- a. Cough
- b. Shortness of breath or have trouble breathing
- c. Chest tightness
- d. Chest pain

Muscles and Joints:

- e. Muscle aches or pains
- f. Joint pain

Gastrointestinal:

- l. Nausea
- m. Vomiting
- n. Diarrhea
- o. Stomach pain
- p. Loss of appetite

Thinking and Feeling:

- p. Dizziness/vertigo
- q. Lightheadedness
- r. Concentration problems
- s. Anxiety
- t. Depression
- u. I had symptoms but none of the symptoms above
- v. I did not have any symptoms
- w. Not sure
- x. Prefer not to answer

Display logic: If (a. I have been diagnosed with COVID-19) or (b. I have been told I may have COVID-19) is selected for “Have you been diagnosed with COVID-19 by a medical professional?”

Multiple choice, single answer, required

31. How long did you experience COVID-19 symptoms?
- a. Less than or equal to 1 month
 - b. More than 1 but less than 2 months
 - c. More than 2 but less than 3 months
 - d. More than 3 but less than 6 months
 - e. More than 6 months

Display Logic: If (a.) through (u.) is selected for “Did you experience any of the following symptoms when you had COVID-19?”

Multiple choice, single answer, required

32. When you had COVID-19 were you hospitalized?
- a. Yes
 - b. No
 - c. I was hospitalized, but don’t know if it was due to COVID-19

Display Logic: If (a. I have been diagnosed with COVID-19) or (b. I have been told I may have COVID-19) is selected for “Have you been diagnosed with COVID-19 by a medical professional?” OR (a. Yes) is selected for “Have you ever received a positive COVID-19 test result while not showing symptoms (asymptomatic COVID-19 infection)?”

Multiple choice, single answer, required

33. When you had COVID-19 were you in the intensive care unit (ICU)?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Display Logic: If (a. Yes) or (c. I was hospitalized, but don't know if it was due to COVID-19) is selected for "When you had COVID-19 were you hospitalized?"

Multiple choice, single answer, required

34. During your hospitalization, were you placed on a ventilator to support your breathing?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Display Logic: If (a. Yes) or (c. I was hospitalized, but don't know if it was due to COVID-19) is selected for "When you had COVID-19 were you hospitalized?"

Multiple choice, single answer, required

35. Have you received a prescription drug treatment for a diagnosed or suspected COVID-19 infection?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Question Display Logic: If (a. I have been diagnosed with COVID-19) or (b. I have been told I may have COVID-19) is selected for "Have you been diagnosed with COVID-19 by a medical professional?" OR (a. Yes) is selected for "Have you ever received a positive COVID-19 test result while not showing symptoms (asymptomatic COVID-19 infection)?"

Multiple choice, single answer, required

36. Were you given COVID-19 treatments into your vein (an IV or infusion) or by injections (a shot)?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Display Logic: If (a. Yes) is selected for "Have you received a prescription drug treatment for diagnosed or suspected COVID-19 infection?"

Multiple choice, multiple answer, required

37. Were you given any of the following treatments for COVID-19? Please select all that apply.

- a. Remdesivir (Veklury)
- b. Convalescent plasma therapy (plasma from someone that has been infected)
- c. Immunoglobulin therapy (IVIG)
- d. Tocilizumab (an antibody against IL-6) (Actemra)
- e. Ascorbic acid & zinc
- f. Monoclonal antibodies to SARS-CoV-2 e.g bamlanivimab and etesevimab, casirivimab plus imdevimab (REGEN-COV), sotrovimab
- g. Dexamethasone
- h. Other treatments into your vein (an IV or infusion) or by injections (a shot)
- i. Not sure

Display Logic: If (a. Yes) is selected for “Were given COVID-19 treatments into your vein (an IV or infusion) or by injections (a shot)?”

Multiple choice, single answer, required

38. Were you given any COVID-19 drugs by mouth (orally)?

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

Display Logic: If (a. Yes) is selected for “Have you received a prescription drug treatment for diagnosed or suspected COVID-19?”

Multiple choice, multiple answer, required

39. Were you given any of the following treatments for COVID-19?

Please select all that apply.

- a. Amantadine
- b. Chloroquine (Aralen)
- c. Hydroxychloroquine (Plaquenil)
- d. Favipiravir (Avigan)
- e. Lopinavir/Ritonavir (Kaletra)
- f. Azithromycin (Zithromax or Z-Pak)
- g. Losartan (Cozaar)
- h. Mavrilimumab (Kiniksa)
- i. Linagliptin (Tradjenta)
- j. Baricitinib (Olumiant)
- k. Tranexamic acid tablets
- l. Ivermectin
- m. Vitamin D
- n. Other oral treatments
- o. Not sure

Display Logic: If (a. Yes) is selected for “Were you given any drugs by mouth (orally)?”

Multiple choice, single answer, required

40. Were you treated for COVID-19 in other ways?

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

Display Logic: If (a. Yes) is selected for “Have you received a prescription drug treatment for diagnosed or suspected COVID-19?”

Multiple choice, multiple answer, required

41. Were you given any of the following treatments for COVID-19? Please select all that apply.

- a. Supplemental oxygen
- b. Hyperbaric oxygen
- c. Nitric oxide
- d. Other
- e. Not sure

Display Logic: If (a. Yes) is selected for “Were you treated for COVID-19 in other ways?”

Multiple choice, single answer, required

42. While you were sick with a diagnosed or suspected case of COVID-19, did you experience **worsening** of your Parkinson’s disease related symptoms?

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

Display Logic: If (a. Yes, I have been diagnosed with Parkinson’s disease) is selected for “Have you been diagnosed with Parkinson’s disease?” AND (a. I have been diagnosed with COVID-19) or (b. I have been told I may have COVID-19) is selected for “Have you been diagnosed with COVID-19 by a medical professional?” OR (a. Yes) is selected for “Have you ever received a positive COVID-19 test result while not showing symptoms (asymptomatic COVID-19 infection)?”

Multiple choice, multiple answer, required

43. Which Parkinson’s disease related *movement* symptoms **worsened** while you were sick with a diagnosed or suspected case of COVID-19?

Please select all that apply.

- a. Problems with walking
- b. Problems with balance
- c. Problems with falling
- d. Shaking or tremor
- e. Slow movements
- f. Stiffness
- g. Problems swallowing pills
- h. Problems eating meals
- i. OFF time - period during which PD medication(s) were not working as well
- j. Dyskinesia - uncontrolled, involuntary movements such as fidgeting, writhing, wriggling, head bobbing, or body swaying
- k. None of the above

Display Logic: If (a. Yes, I have been diagnosed with Parkinson’s disease) is selected for “Have you been diagnosed with Parkinson’s disease?” AND (a. Yes) is selected for “While you were sick with a diagnosed or suspected case of COVID-19, did you experience **worsening** of your Parkinson’s disease related symptoms?”

Multiple choice, multiple answer, required

44. Which Parkinson’s disease related *thinking and feeling* symptoms **worsened** while you were sick with a diagnosed or suspected case of COVID-19?

Please select all that apply.

- a. Difficulty sleeping- trouble getting to sleep or staying asleep through the night (insomnia)
- b. Trouble staying awake during the daytime
- c. Acting out your dreams while asleep - punching, flailing your arms in the air, making running movements, etc.
- d. Trouble thinking clearly, remembering things, and being attentive
- e. Memory loss- trouble remembering things
- f. Confusion - not knowing where you are, the date/time, who familiar people are
- g. Hallucinations - hearing, seeing, feeling, tasting, or smelling something that wasn’t really there
- h. Anxiety - feeling nervous, worried, or tense more than usual
- i. Depression - periods of sadness, hopelessness, emptiness, or loss of enjoyment
- j. Fatigue - physical and mental state of having extremely low energy
- k. Apathy - decreased motivation, initiative, or spontaneity
- l. None of the above

Display Logic: If (a. Yes, I have been diagnosed with Parkinson’s disease) is selected for “Have you been diagnosed with Parkinson’s disease?” AND (a. Yes) is selected for “While you were sick with a diagnosed or suspected case of COVID-19, did you experience **worsening** of your Parkinson’s disease related symptoms?”

Multiple choice, multiple answer, required

45. Which Parkinson’s disease related *bodily function* symptoms **worsened** while you were sick with a diagnosed or suspected case of COVID-19?

Please select all that apply.

- a. Urinary problems - feeling an urgent need to urinate, a need to urinate too often, or having urine accidents
- b. Low blood pressure - feeling light-headed when standing up or sitting up after lying down, sitting, or squatting
- c. Constipation - fewer than three bowel movements a week or having to strain to pass a stool
- d. None of the above

Display Logic: If (a. Yes, I have been diagnosed with Parkinson’s disease) is selected for “Have you been diagnosed with Parkinson’s disease?” AND (a. Yes) is selected for “While you were sick with a diagnosed or suspected case of COVID-19, did you experience **worsening** of your Parkinson’s disease related symptoms?”

Multiple choice, single answer, required

46. While you were sick with a diagnosed or suspected case of COVID-19, did you experience **new** Parkinson's disease related symptoms?

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

Display Logic: (a. Yes, I have been diagnosed with Parkinson's disease) is selected for "Have you been diagnosed with Parkinson's disease?" AND (a. I have been diagnosed with COVID-19) or (b. I have been told I may have COVID-19) is selected for "Have you been diagnosed with COVID-19 by a medical professional?" OR (a. Yes) is selected for "Have you ever received a positive COVID-19 test result while not showing symptoms (asymptomatic COVID-19 infection)?"

Multiple choice, multiple answer, required

47. Which **new** Parkinson's disease related *movement* symptoms did you experience while you were sick with a diagnosed or suspected case of COVID-19?

Please select all that apply.

- a. Problems with walking
- b. Problems with balance
- c. Problems with falling
- d. Shaking or tremor
- e. Slow movements
- f. Stiffness
- g. Problems swallowing pills
- h. Problems eating meals
- i. OFF time - period during which PD medication(s) were not working as well
- j. Dyskinesia - uncontrolled, involuntary movements such as fidgeting, writhing, wriggling, head bobbing, or body swaying
- k. None of the above

Display Logic: If (a. Yes, I have been diagnosed with Parkinson's disease) is selected for "Have you been diagnosed with Parkinson's disease?" AND (a. Yes) is selected for "While you were sick with a diagnosed or suspected case of COVID-19, did you experience **new** Parkinson's disease related symptoms?"

48. Which **new** Parkinson's disease related *thinking and feeling* symptoms did you experience while you were sick with a diagnosed or suspected case of COVID-19?

Please select all that apply.

- a. Difficulty sleeping- trouble getting to sleep or staying asleep through the night (insomnia)
- b. Trouble staying awake during the daytime
- c. Acting out your dreams while asleep - punching, flailing your arms in the air, making running movements, etc.
- d. Trouble thinking clearly, remembering things, and being attentive
- e. Memory loss- trouble remembering things
- f. Confusion - not knowing where you are, the date/time, who familiar people are
- g. Hallucinations - hearing, seeing, feeling, tasting, or smelling something that wasn't really there
- h. Anxiety - feeling nervous, worried, or tense more than usual
- i. Depression - periods of sadness, hopelessness, emptiness, or loss of enjoyment
- j. Fatigue - physical and mental state of having extremely low energy

- k. Apathy - decreased motivation, initiative, or spontaneity
- l. None of the above

Display Logic: If (a. Yes, I have been diagnosed with Parkinson's disease) is selected for "Have you been diagnosed with Parkinson's disease?" AND (a. Yes) is selected for "While you were sick with a diagnosed or suspected case of COVID-19, did you experience **new** Parkinson's disease related symptoms?"

Multiple choice, multiple answer, required

49. Which **new** Parkinson's disease related *bodily function* symptoms did you experience while you were sick with a diagnosed or suspected case of COVID-19?

Please select all that apply.

- a. Urinary problems - feeling an urgent need to urinate, a need to urinate too often, or having urine accidents
- b. Low blood pressure - feeling light-headed when standing up or sitting up after lying down, sitting, or squatting
- c. Constipation - fewer than three bowel movements a week or having to strain to pass a stool
- d. None of the above

Display Logic: If (a. Yes, I have been diagnosed with Parkinson's disease) is selected for "Have you been diagnosed with Parkinson's disease?" AND (a. Yes) is selected for "While you were sick with a diagnosed or suspected case of COVID-19, did you experience **new** Parkinson's disease related symptoms?"

Multiple choice, multiple answer, required

50. While you were sick with a diagnosed or suspected case of COVID-19, did any of your Parkinson's disease related symptoms **improve**?

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

Display Logic: If (a. Yes, I have been diagnosed with Parkinson's disease) is selected for "Have you been diagnosed with Parkinson's disease?" AND (a. I have been diagnosed with COVID-19) or (b. I have been told I may have COVID-19) is selected for "Have you been diagnosed with COVID-19 by a medical professional?" OR (a. Yes) is selected for "Have you ever received a positive COVID-19 test result while not showing symptoms (asymptomatic COVID-19 infection)?"

Multiple choice, multiple answer, required

51. Which Parkinson's disease related *movement* symptoms **improved** with your diagnosed or suspected case of COVID-19?

Please select all that apply.

- a. Problems with walking
- b. Problems with balance
- c. Problems with falling
- d. Shaking or tremor
- e. Slow movements
- f. Stiffness
- g. Problems swallowing pills
- h. Problems eating meals
- i. OFF time - period during which PD medication(s) were not working as well

- j. Dyskinesia - uncontrolled, involuntary movements such as fidgeting, writhing, wriggling, head bobbing, or body swaying
- k. None of the above

Display Logic: If (a. Yes, I have been diagnosed with Parkinson's disease) is selected for "Have you been diagnosed with Parkinson's disease?" AND (a. Yes) is selected for "While you were sick with a diagnosed or suspected case of COVID-19, did any of your Parkinson's disease related symptoms improve?"

Multiple choice, multiple answer, required

52. Which Parkinson's disease related *thinking and feeling* symptoms **improved** with your diagnosed or suspected case of COVID-19?

Please select all that apply.

- a. Difficulty sleeping- trouble getting to sleep or staying asleep through the night (insomnia)
- b. Trouble staying awake during the daytime
- c. Acting out your dreams while asleep - punching, flailing your arms in the air, making running movements, etc.
- d. Trouble thinking clearly, remembering things, and being attentive
- e. Memory loss- trouble remembering things
- f. Confusion - not knowing where you are, the date/time, who familiar people are
- g. Hallucinations - hearing, seeing, feeling, tasting, or smelling something that wasn't really there
- h. Anxiety - feeling nervous, worried, or tense more than usual
- i. Depression - periods of sadness, hopelessness, emptiness, or loss of enjoyment
- j. Fatigue - physical and mental state of having extremely low energy
- k. Apathy - decreased motivation, initiative, or spontaneity
- l. None of the above

Display Logic: (a. Yes, I have been diagnosed with Parkinson's disease) is selected for "Have you been diagnosed with Parkinson's disease?" AND (a. Yes) is selected for "Did any of your Parkinson's disease related symptoms **improve** with a diagnosed or suspected case of COVID-19?"

Multiple choice, single answer, required

53. Which Parkinson's disease related *bodily function* symptoms **improved** with your diagnosed or suspected case of COVID-19?

Please select all that apply.

- a. Urinary problems - feeling an urgent need to urinate, a need to urinate too often, or having urine accidents
- b. Low blood pressure - feeling light-headed when standing up or sitting up after lying down, sitting, or squatting
- c. Constipation - fewer than three bowel movements a week or having to strain to pass a stool
- d. None of the above

Display Logic: If (a. Yes, I have been diagnosed with Parkinson's disease) is selected for "Have you been diagnosed with Parkinson's disease?" AND (a. Yes) is selected for "While you were sick with a diagnosed or suspected case of COVID-19, did any of your Parkinson's disease related symptoms improve?"

Multiple choice, single answer, required

54. Did you experience any new COVID-19 symptoms, or did any of your existing symptoms last **longer than 4 weeks** after your COVID-19 diagnosis?

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

Display Logic: If (a. I have been diagnosed with COVID-19) or (b. I have been told I may have COVID-19) is selected for "Have you been diagnosed with COVID-19 by a medical professional?" OR (a. Yes) is selected for "Have you ever received a positive COVID-19 test result while not showing symptoms (asymptomatic COVID-19 infection)?"

Multiple choice, multiple answer, required

55. Experiencing new or continuing COVID-19 symptoms **longer than 4 weeks** is commonly referred to as **long COVID**. Did you experience any of the following new or continuing long COVID symptoms?

Please select all that apply.

Whole Body:

- k. Fever above 100 F/37.8 C
- l. Chills
- m. Headache
- n. Excessive tiredness or fatigue
- o. Excessive sleepiness such as falling asleep during the day
- p. Difficulty sleeping- trouble getting to sleep or staying asleep through the night (insomnia)
- q. Red, itchy, painful eyes (conjunctivitis or pink eye)
- r. Skin Rash
- s. Sore throat
- t. Nasal congestion or runny nose

Lungs and Heart:

- g. Cough
- h. Shortness of breath or have trouble breathing
- i. Chest tightness
- j. Chest pain

Muscles and Joints:

- k. Muscle aches or pains
- l. Joint pain

Gastrointestinal:

- q. Nausea
- r. Vomiting
- s. Diarrhea
- t. Stomach pain
- u. Loss of appetite

Thinking and Feeling:

- y. Dizziness/vertigo

- z. Lightheadedness
- aa. Concentration problems
- bb. Anxiety
- cc. Depression
- a. I had long COVID symptoms but none of the symptoms above
- b. Not sure
- c. Prefer not to answer

Display Logic: If (a. Yes) is selected for “Did you experience any new COVID-19 symptoms, or did any of your existing symptoms last longer than 4 weeks after your COVID-19 diagnosis?”

56. For how long did you experience long COVID symptoms?

- a. 1 month
- b. More than 1 but less than 2 months
- c. More than 2 but less than 3 months
- d. More than 3 but less than 6 months
- e. More than 6 months

Display Logic: If (a.) through (m.) is selected for “Did you experience any of the following long COVID symptoms?”

Multiple choice, single answer, required

57. Some people experience medical conditions following their COVID-19 infection that are **diagnosed by a medical professional.**

Were you diagnosed with any of the following after a diagnosed or suspected case of COVID-19? Please select all that apply.

- a. Post-traumatic Stress Disorder (PTSD)
- b. Multiple organ failure
- c. Multisystem Inflammatory Syndrome (MIS)
- d. Autoimmune conditions
- e. I was not diagnosed with any of these conditions
- f. Not sure
- g. Prefer not to answer

Display Logic: If (a. Yes) is selected for “Did you experience any new COVID-19 symptoms, or did any of your existing symptoms last **longer than 4 weeks** after your COVID-19 diagnosis?”

Multiple choice, single answer, required

58. For how long did you experience these conditions (PTSD, multiple organ failure, MIS, and/or autoimmune conditions)?

- a. 1 month
- b. More than 1 but less than 2 months
- c. More than 2 but less than 3 months
- d. More than 3 but less than 6 months
- e. More than 6 months

Display Logic: If (a.) through (d.) is selected for “Were you diagnosed with any of the following after a diagnosed or suspected case of COVID-19?”

Part 3: Environment and Health History

These questions ask about your environment and health history.

Multiple choice, single answer, required

59. Please tell us a little about where you currently live:

- a. Single family home or mobile home
- b. Apartment or co-op
- c. Living in a dormitory, military barracks, religious order, or other shared living environment
- d. Senior independent living facility
- e. Assisted living facility
- f. Skilled nursing facility
- g. Currently experiencing housing insecurity or homelessness
- h. Other

Drop-down, single answer, required

60. How many people live (or are currently staying) in your household **including yourself?**

[Drop-down of variables from 1-15 people, More than 15 people]

Display Logic: If (a. Single family home or mobile home) or (b. Apartment or co-op) selected for “Please tell us a little about where you currently live:”

Multiple choice, single answer, required

61. What is the approximate number of people living in your facility **including yourself?**

- a. 1-10 people
- b. 11-30 people
- c. 31-50 people
- d. More than 50 people

Display Logic: If (c. Living in a dormitory, military barracks, religious order, or other shared living environment), (d. Senior independent living facility), (e. Assisted living facility), or (f. Skilled nursing facility) is selected for “Please tell us a little about where you currently live:”

Text entry, single answer, required

62. What are the **first 3 numbers/letters** of your zip code or postal code?

[Text Box]

Multiple choice, single answer, required

63. Please describe the area/region you live in:

- a. City or large metropolitan area
- b. Town or village
- c. Rural
- d. Other

Multiple choice, multiple answer, required

64. Please select any of the following behaviors or conditions that you currently have or previously had in the past:

Please select all that apply.

- a. Current smoker
- b. Former smoker
- c. Heart disease
- d. High blood pressure
- e. Chronic lung disease (for example: asthma, chronic obstructive pulmonary disease (COPD), emphysema, etc.)
- f. Diabetes mellitus
- g. HIV or AIDS
- h. Had chemotherapy within the past year
- i. Taking steroid medications by mouth
- j. Taking immune suppressing medication, such as those to treat for rheumatoid arthritis or inflammatory bowel disease
- k. None of the above

The next set of questions will help us understand whether social distancing or stay at home guidelines related to the COVID-19 pandemic affected your everyday life.

Multiple choice, single answer, required

65. Was your ability to obtain medications affected?
- a. Yes
 - b. No
 - c. I do not take medications
 - d. Not sure
 - e. Prefer not to answer

Multiple choice, single answer, required

66. Was your ability to obtain medications **for your Parkinson's disease** affected?
- a. Yes
 - b. No
 - c. I do not take PD medications
 - d. Not sure
 - e. Prefer not to answer

Display Logic: If (a. I have been diagnosed with Parkinson's disease) is selected for "Please share your health status" AND (a. Yes) is selected for "Was your ability to obtain medications affected?"

Multiple choice, single answer, required

67. Did you have any medical treatments cancelled or postponed as a result of the COVID-19 pandemic?
- a. Yes
 - b. No
 - c. Not applicable
 - d. Not sure
 - e. Prefer not to answer

Multiple choice, multiple answer, required

68. Which of the following treatments related to your Parkinson's disease were cancelled or postponed as a result of the COVID-19 pandemic?

Please select all that apply.

- a. Visit with PD neurologist
- b. Botulinum toxin injections
- c. Deep Brain Stimulation (DBS) surgery
- d. Deep Brain Stimulation (DBS) battery replacement
- e. Deep Brain Stimulation (DBS) programming
- f. Other
- g. None of the above

Display Logic: If (a. Yes, I have been diagnosed with Parkinson's disease) is selected for "Have you been diagnosed with Parkinson's disease" AND (a. Yes) to "Did you have any medical treatments cancelled or postponed as a result of the COVID-19 pandemic?"

Multiple choice, multiple answer, required

69. Have you experienced a disruption in any of the following daily needs or services as a result of the COVID-19 pandemic?

Please select all that apply.

- a. I had problems getting food
- b. I had problems getting household essentials (toilet paper, cleaning supplies, etc.)
- c. I had problems getting help with my usual homecare/housekeeping
- d. I had problems getting help with my usual personal care assistance
- e. None of the above

Multiple choice, single answer, required

70. How have your **household finances** been negatively impacted as a result of the COVID-19 pandemic?

Please select all that apply.

- a. Household income declined
- b. Household savings or retirement funds declined
- c. Difficulty paying rent or mortgage
- d. Difficulty paying other bills
- e. Household finances were not negatively impacted
- f. Other

Part 4: The impact of the COVID-19 pandemic on care partners of people with Parkinson's disease

The next set of questions is about the effects of the COVID-19 pandemic on care partners of people with Parkinson's disease.

Multiple choice, single answer, required

71. Do you identify yourself as a care partner for someone with Parkinson's disease?

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

Display logic: if (b. No, I have not been diagnosed with Parkinson's disease) is selected for "Have you been diagnosed with Parkinson's disease?"

Skip Logic: If (b) or (c) (d) is selected, skip to end of survey

Multiple choice, single answer, required

72. Do you identify yourself as an informal/**non-paid** care partner for someone with Parkinson's disease?

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

Display logic: if (b. No, I have not been diagnosed with Parkinson's disease) is selected for "Have you been diagnosed with Parkinson's disease?"

Skip Logic: If (b), (c) or (d) is selected, skip to end of survey

Multiple choice, single answer, required

73. Do you identify yourself as a **primary** care partner for a person with Parkinson's disease?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Display logic: if (b. No, I have not been diagnosed with Parkinson's disease) is selected for "Have you been diagnosed with Parkinson's disease?"

Text entry, limited to two digits between 0-99, single answer, required

74. How many years ago was the person you care for diagnosed with Parkinson's disease?

Display logic: if (b. No, I have not been diagnosed with Parkinson's disease) is selected for "Have you been diagnosed with Parkinson's disease?"

Multiple choice, multiple answer, required

75. **For the past month during the COVID-19 pandemic**, has the person with Parkinson's disease suffered from any of the following symptoms?
Please select all that apply.

- a. Falls
- b. Depressed mood
- c. Anxious mood
- d. Apathy or a loss of motivation
- e. Difficulty with memory or thinking
- f. Hallucinations/psychosis
- g. None of the above

Display logic: if (b. No, I have not been diagnosed with Parkinson's disease) is selected for "Have you been diagnosed with Parkinson's disease?"

Multiple choice, multiple answer, required

76. **For the past week during the COVID-19 pandemic**, did the person with Parkinson's disease usually:
Please select all that apply.

- a. Have problems swallowing pills or eating meals
- b. Have trouble handling their food and using eating utensils
- c. Need help dressing
- d. Move slowly, or need help with washing, bathing, shaving, brushing teeth, combing their hair, or with other personal hygiene
- e. Have trouble getting out of bed, a car seat, or a deep chair
- f. Have trouble with control of urine
- g. Have constipation
- h. None of the above

Display logic: if (b. No, I have not been diagnosed with Parkinson's disease) is selected for "Have you been diagnosed with Parkinson's disease?"

Multiple choice, multiple answer, required

77. Which of the following responsibilities did you have as a care partner over the **past week**?

Please select all that apply.

- a. Assisting with personal care (e.g., help with bathing, grooming, dressing, etc.)
- b. Food preparation
- c. Feeding
- d. Obtaining and/or administering prescribed medications
- e. General health care (such as scheduling medical appointments, making sure they get to appointments, etc., but does not include administering medications)
- f. Mobility assistance (e.g., helping them getting up from a chair, assisting with balance)
- g. Providing emotional support
- h. Transportation
- i. Home organization (e.g., cleaning and organizing the home)
- j. Handling a crisis or medical emergency
- k. Financial responsibilities
- l. Grocery shopping and errands
- m. None of the above

Display logic: if (b. No, I have not been diagnosed with Parkinson's disease) is selected for "Have you been diagnosed with Parkinson's disease?"

Multiple choice, single answer, required

78. Do you attend support groups for Parkinson's disease for your own benefit or support groups for care partners?

- a. Yes, in person
- b. Yes, but virtually
- c. I used to, but not anymore due to the COVID pandemic
- d. No
- e. Not sure
- f. Prefer not to answer

Display logic: if (b. No, I have not been diagnosed with Parkinson's disease) is selected for "Have you been diagnosed with Parkinson's disease?"

Scale, multiple answer, single answer required per row

79. Here is a list of things that other care partners have found to be difficult. Please put a checkmark in the columns that apply to you. We have included some examples that are common caregiver experiences to help you think about each item. Your situation may be slightly different, but the item could still apply.

	a. Yes, on a regular basis	b. Yes, sometimes	c. No
My sleep is disturbed – For example: the person I care for is in and out of bed or wanders around at night	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Caregiving is inconvenient – For example: helping takes so much time or it's a long drive over to help	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Caregiving is a physical strain – For example: lifting in or out of a chair; effort of concentration is required	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Caregiving is confining – For example: helping restricts free time or I cannot go visiting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There have been family adjustments – For example: helping has disrupted my routine; there is no privacy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There have been changes in my personal plans – For example: I had to turn down a job; I could not go on vacation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There have been other demands of my time – For example: other family members need me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

<p>There have been emotional adjustments – For example: severe arguments about caregiving</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<p>Some behavior is upsetting – For example: incontinence; the person care for has trouble remembering things; or the person I care for accuses people of taking their things</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<p>It is upsetting to find the person I care for has changed so much from his/her former self – For example: he/she is a different person than he/she used to be</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<p>There have been work adjustments – For example: I have to take time off for caregiving duties</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<p>Caregiving is a financial strain</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<p>I feel completely overwhelmed – For example: I worry about the person I care for; I have concerns about how I will manage</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Display logic: if (b. No, I have not been diagnosed with Parkinson’s disease) is selected for “Have you been diagnosed with Parkinson’s disease?”

Scale, multiple answer, single answer required per row

80. In the prior question, you rated the following things as regularly or sometimes difficult. In comparison to **BEFORE** the COVID-19 pandemic, has this issue:

	a. Increased	b. Remained the same	c. Decreased
My sleep is disturbed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Caregiving is inconvenient	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Caregiving is a physical strain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Caregiving is confining	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There have been family adjustments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There have been changes in my personal plans	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There have been other demands of my time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There have been emotional adjustments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Some behavior is upsetting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is upsetting to find the person I care for has changed so much from his/her former self	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There have been work adjustments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Caregiving is a financial strain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel completely overwhelmed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Display Logic: If (a. Yes on a regular basis) or (b. Yes, sometimes) is selected for any item in the first matrix, corresponding item will be displayed in this matrix.

Multiple choice, multiple answer, required

81. How did the COVID-19 pandemic contribute to your burden as a care partner?

Please select all that apply.

- a. Social isolation
- b. Difficulty accomplishing tasks of daily life outside the home
- c. Concern over your own health
- d. Increase in symptoms or decline in health of the person with Parkinson's disease you care for

- e. Reduced access to health care services
- f. Reduced health from paid care partners
- g. Reduced help from family and friends
- h. Not being able to do the things that give you joy
- i. The COVID-19 pandemic did not contribute to my burden as a care partner
- j. None of the above

Skip Logic: If (i. The COVID-19 pandemic did not contribute to my burden as a care partner) is selected, skip to end of survey

Multiple choice, multiple answer, less than or equal to 3 responses allowed, required

82. How did the COVID-19 pandemic contribute to your burden as a care partner?

Please select up to **three** of the following that contributed the most to your burden.

- a. Social isolation
- b. Difficulty accomplishing tasks of daily life outside the home
- c. Concern over your own health
- d. Increase in symptoms or decline in health of the person with Parkinson's disease you care for
- e. Reduced access to health care services
- f. Reduced health from paid care partners
- g. Reduced help from family and friends
- h. Not being able to do the things that give you joy
- i. None of the above
- j. Prefer not to answer

End of Survey

Thank you for sharing your experiences during the COVID-19 pandemic. **Please click on the next arrow below (>>) to submit your responses and be redirected to the Fox Insight website.**