

**Understanding Psychosis and its Burden on Caregivers
July 2019**

INTRO TO SURVEY - The Michael J. Fox Foundation for Parkinson’s Research (MJFF) seeks to understand unmet needs of Parkinson’s patients. With this goal, the current research explores how caregivers experience, and communicate about, their life of caring for someone with Parkinson’s disease and certain PD symptoms specifically.

MULTIPLE CHOICE, SINGLE ANSWER, OPTIONAL
NEW SCREEN

- Q1. What is your relationship to the person you care for with Parkinson’s disease?
- a. They are my spouse/partner
 - b. They are my parent
 - c. They are my sibling
 - d. They are my aunt or uncle
 - e. They are my employer
 - f. Some other relationship (Please specify in box below)

MULTIPLE CHOICE, SINGLE ANSWER, OPTIONAL
NEW SCREEN

- Q9. Are you the principal caregiver for your (INSERT RELATIONSHIP)?

By principal caregiver we mean the person who provides majority, if not all, of the care to the person you know who has Parkinson’s disease.

- a. Yes
- b. No

MULTIPLE CHOICE, SINGLE ANSWER, OPTIONAL
NEW SCREEN

- Q7. Which of the following best describes your role as a caregiver?

Please select one.

- a. I am not a paid caregiver and I live with my (INSERT RELATIONSHIP)
- b. I am not a paid caregiver and I do not live with my (INSERT RELATIONSHIP)
- c. I am a paid caregiver and I live with my (INSERT RELATIONSHIP)
- d. I am a paid caregiver and I do not live with my (INSERT RELATIONSHIP)

OPEN END, TEXT ENTRY, OPTIONAL
ALLOW 2 DIGIT NUMBER RANGE 18 - 99
NEW SCREEN

Q2. What is the age of your (INSERT RELATIONSHIP)?

[ENTER 2 DIGIT NUMBER RANGE 18-99]

OPEN END, TEXT ENTRY, OPTIONAL
ALLOW 4 DIGIT NUMBER RANGE 1989-2019 OR SELECT OPTION "Prior to 1989"
NEW SCREEN

Q3. When was your (INSERT RELATIONSHIP) diagnosed with Parkinson's disease?

Please type the year they were diagnosed below. Your best estimate is fine.

[ENTER 4 DIGIT YEAR] Range 1989 – 2019

b. Prior to 1989

OPEN END, TEXT ENTRY, OPTIONAL
ALLOW 4 DIGIT NUMBER RANGE ANSWER TO QX – 2019
IF 'Prior to 1989' IS SELECTED AT QX, INCLUDE AS OPTION
NEW SCREEN

Q4. When did you first become a caregiver for your (INSERT RELATIONSHIP)?

Please type in your response below. Your best estimate is fine.

[OPEN END]

b. Prior to 1989

MULTIPLE CHOICE, SINGLE ANSWER, OPTIONAL
NEW SCREEN

Q5. How much time per week do you spend caring for your (INSERT RELATIONSHIP)?

Please select the response which best describes your role.

- a. I care for my (INSERT RELATIONSHIP) full time
- b. I care for my (INSERT RELATIONSHIP) a few hours a day every day, but I am not with them full time
- c. I care for my (INSERT RELATIONSHIP) a few days a week, but do not provide care for them every day
- d. I care for my (INSERT RELATIONSHIP) one day during the week or less

MULTIPLE CHOICE, MULTI SELECT ANSWER, OPTIONAL
NEW SCREEN

Q6. Which of the following responsibilities do you have as a caregiver?

Please select all that apply.

- a. Assisting with personal care (e.g., helping with bathing, grooming, dressing, etc.)
- b. Food preparation
- c. Obtaining and/or administering prescribed medications
- d. General health care (such as scheduling medical appointments, making sure they get to appointments, etc., but does not include medications)
- e. Mobility assistance (e.g., helping them getting up from a chair, assisting with balance)
- f. Providing emotional support
- g. Transportation
- h. Home organization (e.g., cleaning and organizing the home)
- i. Handling a crisis or medical emergency
- j. Financial responsibilities
- k. Another responsibility (Please specify in the box below)

MULTIPLE CHOICE, SINGLE ANSWER, OPTIONAL
NEW SCREEN

Q8. Do you currently work outside the home?

- a. Yes
- b. No

MULTIPLE CHOICE, MULTI SELECT ANSWER, OPTIONAL
RANDOMIZE OPTIONS a-f
NEW SCREEN

Q11. What physical symptoms, if any, do you associate with being a caregiver of someone with Parkinson's disease?

Please select all the symptoms that you experience (not the person you are caring for experiences).

- a. Changes in weight
- b. Difficulty sleeping
- c. Headaches
- d. Physical pain
- e. Exhaustion
- f. Hair loss
- g. Some other physical symptom/s (Please specify in the box below)
- h. Have not experienced any physical symptoms

MULTIPLE CHOICE, MULTI SELECT ANSWER, OPTIONAL

RANDOMIZE OPTIONS a-f

NEW SCREEN

Q12. What strategies, if any, do you find are most helpful to cope with the challenges of caregiving for someone with Parkinson's disease?

Please select up to three strategies.

- a. Talking to a family member or friend
- b. Participating in support groups (in-person or online)
- c. Receiving mental health counseling (e.g., speak to a therapist)
- d. Getting away from the caregiver role (e.g., working in the yard, going grocery shopping, taking time off, etc.)
- e. Exercising
- f. Meditating
- g. Some other coping strategy (Please specify in the box below)
- h. Nothing is helpful to cope with the burden of being a caregiver

NEW SCREEN

RANDOMIZE SCALES SHOWN TO RESPONDENTS CBI/NPIQ

INSERT CAREGIVER BURDEN INVENTORY ASSESSMENT & NPI Q SCALE

IF PD PATIENT EXPERIENCES PSYCHOSIS SYMPTOMS (BASED ON NPIQ), CONTINUE WITH SURVEY

IF PD PATIENT DOES NOT EXPERIENCE PSYCHOSIS SYMPTOMS (BASED ON NPIQ), SURVEY ENDS HERE

TEXT TO BE DISPLAYED ON TOP OF EACH SCREEN STARTING AT Q13.

T1. For the purpose of this survey, please think of psychosis as symptoms such as hallucinations, delusions and/or paranoia that can sometimes occur in Parkinson's disease. Hallucinations are perceptions that something is present when it is not (such as, seeing someone or something that is not there). Delusions are having false beliefs (such as, believing items are being stolen from the home) and paranoia is unrealistic suspiciousness (such as, thinking someone is out to get you). PD psychosis can be associated with having one or more of these symptoms.

OPEN END, TEXT ENTRY, OPTIONAL

ALLOW 4 DIGIT NUMBER ONLY (RANGE ANSWER TO Q3 – 2019)

NEW SCREEN

Q13. You mentioned the person you care for with Parkinson's disease experiences psychosis symptoms. In what year did your (INSERT RELATIONSHIP) start experiencing Parkinson's disease psychosis symptoms?

Please type the year the psychosis symptoms began.

[OPEN END]

MULTIPLE CHOICE, SINGLE ANSWER, OPTIONAL
NEW SCREEN

Q14. As far as you know, are there any medications available to treat Parkinson's disease psychosis symptoms (i.e., hallucinations, delusions, and/or paranoia), or not?

- a. Yes
- b. No

MULTIPLE CHOICE, SINGLE ANSWER, OPTIONAL
NEW SCREEN

Q15. You indicated the person you care for with Parkinson's disease experiences psychosis symptoms. Do they currently take any medication(s) specifically to treat these psychosis symptoms (i.e., hallucinations, delusions, and/or paranoia), or not?

- a. Yes
- b. No
- c. I do not know

MULTIPLE CHOICE, MULTI SELECT ANSWER, OPTIONAL
NEW SCREEN

Q10. Does the person you care for take any of the following medication(s)?

Please select all that apply.

- a. Pimavanserin (Nuplazid)
- b. Quetiapine (Seroquel)
- c. Risperidone (Risperdal)
- d. Olanzapine (Zyprexa)
- e. Clozapine (Clozaril)
- f. Haloperidol (Haldol)
- g. Donepezil (Aricept)
- h. Rivastagimine (Exelon)
- i. Memantine (Namenda)
- j. Clonazepam (Klonopin)
- k. Lorazepam (Ativan)
- l. None of the above
- m. I do not know the medication(s) they currently take

MULTIPLE CHOICE, MULTI SELECT ANSWER, OPTIONAL

(IF Q15=a [Yes])

RANDOMIZE a-b

NEW SCREEN

Q16. What prompted your (INSERT RELATIONSHIP)'s health care provider to prescribe medication to treat their psychosis symptoms?

Please select all that apply.

- a. They became a danger to themselves
- b. They became a danger to others
- c. As a caregiver, I could no longer provide adequate care due to their psychosis symptoms
- d. Their psychosis symptoms were scaring or otherwise negatively impacting me as a caregiver
- e. The psychosis symptoms were scaring or otherwise negatively impacting my (INSERT RELATIONSHIP)
- f. Some other reason (Please specify in the box below)

MULTIPLE CHOICE, SINGLE ANSWER, OPTIONAL

(IF Q15=b [No])

NEW SCREEN

Q17. How likely are you to advocate for medicine to treat the psychosis symptoms of the person you care for with Parkinson's disease?

- a. Very likely
- b. Somewhat likely
- c. Slightly likely
- d. Not at all likely

MULTIPLE CHOICE, MULTI SELECT ANSWER, OPTIONAL

(IF Q15=b [No] AND Q17= "b", "c", or "d" [Somewhat, slightly or not at all likely])

RANDOMIZE OPTIONS a-e, KEEP OPTIONS a-b AND c-d TOGETHER, SHOW b AFTER a AND SHOW d AFTER c

NEW SCREEN

Q18. What would make you more likely to advocate for medicine to treat the psychosis symptoms of your (INSERT RELATIONSHIP)?

Please select up to three.

- a. If they became a danger to themselves due to their psychosis symptoms
- b. If the psychosis symptoms were negatively impacting the patient in other ways than being a danger to themselves
- c. If they became a danger to you (the caregiver) or others due to their psychosis symptoms
- d. If the psychosis symptoms were negatively impacting me as a caregiver in other ways than feeling as if I was in danger
- e. If I could no longer care for them due to the psychosis symptoms they were experiencing
- f. Some other reason (Please specify in the box below)
- g. Nothing would make me more likely to advocate for medication to treat psychosis symptoms

MULTIPLE CHOICE, MULTI SELECT ANSWER, OPTIONAL
NEW SCREEN

Q19. How do you communicate with the health care providers (e.g., doctor, nurse practitioner, or physician assistant) your (INSERT RELATIONSHIP) sees for their Parkinson's disease about their psychosis symptoms?

Please select all that apply.

- a. During the appointment, with my (INSERT RELATIONSHIP) in the room
- b. During the appointment, but without my (INSERT RELATIONSHIP) in the room
- c. Through an online patient portal (outside of appointments)
- d. Through emails to the doctor, without my (INSERT RELATIONSHIP) knowing
- e. Some other way (Please specify in the box below)
- f. I have never communicated with the doctor about my (INSERT RELATIONSHIP)'s psychosis symptoms

MULTIPLE CHOICE, SINGLE ANSWER, OPTIONAL
(IF Q19=any a-e [Communicates with doctor about psychosis symptoms])
RANDOMIZE OPTIONS a-d
NEW SCREEN

Q19a. Based on communication(s) you've had with your (INSERT RELATIONSHIP)'s doctor about their psychosis symptoms, which, if any, of the following happened?

Please select all that apply.

- a. The doctor gave the person I care for a new medication to take
- b. The doctor adjusted or stopped current medication(s)
- c. The doctor referred my (INSERT RELATIONSHIP) to another health care provider
- d. The doctor ordered tests to be done
- e. Another decision was made (Please specify in the box below)
- f. None of the above/The doctor did not think the symptoms were serious enough to require treatment

MULTIPLE CHOICE, SINGLE ANSWER, OPTIONAL
NEW SCREEN

Q20. How do you most prefer to communicate with the doctor your (INSERT RELATIONSHIP) sees for their Parkinson's disease about their psychosis symptoms?

- a. During the appointment, with my (INSERT RELATIONSHIP) in the room
- b. During the appointment, but without my (INSERT RELATIONSHIP) in the room
- c. Through an online patient portal (outside of appointments)
- d. Through emails to the doctor, without my (INSERT RELATIONSHIP) knowing
- e. Some other way (Please specify in the box below)
- f. I do not feel the need to communicate with the doctor about my (INSERT RELATIONSHIP)'s psychosis symptoms

MULTIPLE CHOICE, MULTI SELECT ANSWER, OPTIONAL

(IF Q19=f [No, has never communicated about psychosis symptoms with doctor])

RANDOMIZE OPTIONS a-g

NEW SCREEN

Q21. Why have you not previously discussed the psychosis symptoms the person you care for experiences with their doctor?

Please select all that apply.

- a. I feel there is nothing the doctor can do about it.
- b. I feel it's a normal part of the disease.
- c. Psychosis is not as bothersome as other symptoms and I focus on the more bothersome symptoms when speaking with the doctor.
- d. I can manage the psychosis, so I don't feel it's necessary to discuss.
- e. I feel discussing the psychosis embarrasses my (INSERT RELATIONSHIP), so I don't want to talk about it in front of them.
- f. There is not enough time during the appointments to discuss the psychosis symptoms.
- g. I didn't know psychosis symptoms (i.e., hallucinations, delusions, and/or paranoia) were related to Parkinson's disease
- h. Some other reason (Please specify in the box below)

MULTIPLE CHOICE, MULTI SELECT ANSWER, OPTIONAL

(IF Q19=a-e [Communicates with doctor about psychosis symptoms])

RANDOMIZE OPTIONS a-f

NEW SCREEN

Q22. What challenges, if any, do you experience when discussing psychosis symptoms with your (INSERT RELATIONSHIP)'s doctor?

Please select all that apply.

- a. I do not want to speak about these symptoms in front of the patient I care for
- b. I do not want to embarrass the patient by discussing these symptoms
- c. The person I care for is reluctant to share this information with the doctor, so we do not discuss the symptoms
- d. The doctor does not ask about it
- e. There is not enough time during the appointments to discuss the psychosis symptoms
- f. There are more pressing and/or important items/symptoms to discuss during the appointments than the psychosis symptoms
- e. Some other challenge (Please specify in the box below)
- f. There are no challenges in discussing psychosis symptoms with the doctor

MULTIPLE CHOICE, MULTI SELECT ANSWER, OPTIONAL

RANDOMIZE OPTIONS a-g

NEW SCREEN

Q23. When your (INSERT RELATIONSHIP) is experiencing psychosis symptoms, what strategies, if any, do you find most helpful to handle the psychosis episode?

Please select up to three strategies.

- a. Going along with it (e.g., “shoo-ing” away the “people in the yard”)
- b. Trying to convince them they are not seeing, hearing, or feeling what they claim is happening
- c. Attempting to distract them (e.g., putting on music or going for a walk)
- d. Trying to relax them by giving calming reassurance and support
- e. Gently restraining them
- f. Calling in help
- g. Removing yourself from the situation
- h. Some other coping strategy (Please specify in the box below)
- i. I do not find anything helpful when the person I care for is experiencing psychosis symptoms

MULTIPLE CHOICE, MULTI SELECT ANSWER, OPTIONAL

RANDOMIZE OPTIONS a-g

NEW SCREEN

Q24. Thinking about when your (INSERT RELATIONSHIP) has had PD psychosis symptoms, which of the following emotions, if any, have you experienced?

Please select all that apply.

- a. Embarrassment
- b. Being uncomfortable
- c. Depression and/or sadness
- d. Frustration
- e. Feeling overwhelmed
- f. Fear
- g. Anxiety/Feeling anxious
- h. Another emotion (Please specify in the box below)
- i. I do not experience emotions when thinking about psychosis symptoms

MULTIPLE CHOICE, SINGLE ANSWER, OPTIONAL

RANDOMIZE OPTIONS a-f

NEW SCREEN

Q25. How did you first learn about Parkinson's disease psychosis?

- a. The doctor of the patient I care for with Parkinson's disease informed me about psychosis
- b. When the person I care for started experiencing psychosis symptoms
- c. Someone at a support group informed me
- d. From a PD organization such as Parkinson's Foundation, MJFF, APDA
- e. Research I did myself online or through books
- f. From a television commercial
- h. Some other way (Please specify in the box below)

OPEN END, TEXT ENTRY, OPTIONAL

NEW SCREEN

Q26. You mentioned the person you care for experiences psychosis symptoms. What one piece of advice would you give to a caregiver when the person they care for first starts experiencing psychosis symptoms (i.e., hallucinations, delusions and/or paranoia)?

[OPEN END]

MULTIPLE CHOICE, MULTI SELECT ANSWER, OPTIONAL

RANDOMIZE OPTIONS a-g

NEW SCREEN

Q27. What information, if any, would have been most helpful to have when the person you care for with Parkinson's disease started experiencing psychosis symptoms?

Please select up to three.

- a. Information on the causes of psychosis
- b. Information on the treatments for psychosis in PD
- c. Information on medication to treat psychosis symptoms
- d. Information on support groups
- e. Information on how best to handle the person you care for when they experience a psychosis episode
- f. Information explaining the symptoms of psychosis (i.e., hallucinations, delusions, and paranoia)
- g. Information on books and/or articles to read about psychosis symptoms
- h. Some other type of information (Please specify in the box below)
- i. None