

Care Partner Experiences

Parts of this survey were adapted for Fox Insight from the following sources:

Care partner experiences of daily living section, Q19-32, questions were adapted from the following source:

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Care partner work impact section, Q33-38, questions were adapted from the following source:

Zhang W, Bansback N, Boonen A, Young A, Singh A, Anis AH. Validity of the work productivity and activity impairment questionnaire--general health version in patients with rheumatoid arthritis. *Arthritis Res Ther*. 2010;12(5):R177. doi:10.1186/ar3141

Care partner burden section, Q39-40, questions were adapted from the following source:

Zarit Burden Interview (ZBI-22). Zarit SH, Zarit JM. The Memory and Behavior Problems Checklist and the Burden Interview. Gerontology Center, Penn State University. 1990

Care partner coping section, Q42-43, questions were adapted from the following source:

Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the Brief COPE. *International Journal of Behavioral Medicine*, 4, 92-100.

Care partner needs section, Q44-48, questions were adapted from the following source:

Campbell SH, Carey M, Sanson-Fisher R, Barker D, Turner D, Taylor-Brown J, Hall A. Measuring the unmet supportive care needs of cancer support persons: the development of the support person's unmet needs survey--short form. *Eur J Cancer Care (Engl)*. 2014 Mar;23(2):255-62. doi: 10.1111/ecc.12138. Epub 2013 Oct 15. PMID: 24127743.

Care Partner Experiences

Introduction

Thank you for your interest in completing this survey. The purpose of this survey is to better understand the experiences of those who care for someone with Parkinson's disease (PD), sometimes referred to as care partners. **A care partner is someone who regularly provides support to a person with a health condition so that they can meet their day-to-day care needs, such as through physical, emotional or social support.** We will ask you questions about the many aspects of being a care partner, such as your role as a care partner, the burden of care, needs that may or may not need to be met and coping strategies you may use. We will also ask you some questions about the person with PD that you care for. Your answers will help us understand how best to support care partners of people with PD.

[BLOCK 1] Care partner demographics

Please select the correct answer.

Multiple choice, single answer, required

1. Do you currently have a diagnosis of Parkinson's disease, or parkinsonism, by a physician or other health care professional?
 - a. Yes
 - b. No

Skip Logic: If (a. Yes) is selected, skip to end of survey 2.

Multiple choice, single answer, required

2. Do you identify yourself as a care partner for someone with Parkinson's disease?
A care partner is someone who regularly provides support to a person with a health condition so that they can meet their day-to-day care needs, such as through physical, emotional or social support.
 - a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Skip Logic: If (b. No), (c. Not sure) or (d. Prefer not to answer) is selected, skip to end of survey 3.

Multiple choice, single answer, required

3. Do you identify yourself as an informal/**non-paid** care partner for a person with Parkinson's disease?
 - a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Display Logic: If (a. Yes) is selected for "Do you identify yourself as a care partner for someone with Parkinson's disease?"

Skip Logic: If (b. No), (c. Not sure) or (d. Prefer not to answer) is selected, skip to end of survey 4.

Multiple choice, single answer, required

4. 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 (a. Yes) is selected for "Do you identify yourself as an informal/non-paid care partner for a person with Parkinson's disease?"

5. What is your relationship to the person with Parkinson's? The person with Parkinson's is my:
 - a. Spouse
 - b. Parent
 - c. Other family member
 - d. Other
 - e. Prefer not to answer

Multiple choice, single answer, required

6. Other than your care partner responsibilities for the person with PD, did you help care for anyone else during the past 4 weeks?
- a. Yes, I am the primary care provider for someone else
 - b. Yes, I am the secondary care provider for someone else
 - c. No, I do not provide care for anyone else
 - d. Not sure
 - e. Prefer not to answer

Multiple choice, multiple answer, required

7. Who else did you help care for?
- a. Parent(s)
 - b. Spouse
 - c. Child, children
 - d. Other family member(s)
 - e. Other

Display Logic: If (a. Yes, I am the primary care provider for someone else) or (b. Yes, I am the secondary care provider for someone else) is selected for Q6

Multiple choice, single answer, required

8. Did you receive assistance from anyone else to help you with your care partner responsibilities during the past 4 weeks?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Multiple choice, single answer, required

9. 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. No
 - d. Not sure
 - e. Prefer not to answer

Demographics of the person with Parkinson's

We would like to better understand your experiences as a care partner of someone with Parkinson's disease. The next few questions will ask you to provide information about the person with Parkinson's.

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

10. What is the age of the person with Parkinson's? If you are not sure, please make your best guess.
Age: _____

Multiple choice, single answer, required

11. What is the gender of the person with Parkinson's?

- a. Male
- b. Female
- c. Other
- d. Not sure
- e. Prefer not to answer

Multiple choice, single answer, required

12. What is the race of the person with Parkinson's?

- a. American Indian or Alaska Native
- b. Asian
- c. Black or African American
- d. Native Hawaiian or Other Pacific Islander
- e. White or Caucasian
- f. Other
- g. Not sure
- h. Prefer not to answer

13. What is the ethnicity of the person with Parkinson's? Are they Hispanic, Latino/a, or Spanish Origin? Please select all that apply.

- a. No, not of Hispanic, Latino/a, or Spanish Origin
- b. Yes, Mexican, Mexican American, Chicano/a
- c. Yes, Puerto Rican
- d. Yes, Cuban
- e. Yes, another Hispanic, Latino/a, or Spanish origin

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

14. How many years ago was the person with Parkinson's diagnosed? If you are not sure, please make your best guess.

Years: _____

Multiple choice, single answer, required

15. Within the past 12 months, did the person with Parkinson's have to visit the emergency room due to Parkinson's disease?

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

Multiple choice, single answer, required

16. Within the past 12 months, has the person with Parkinson's been hospitalized due to Parkinson's disease?

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

Care partner roles

Multiple choice, multiple answer, required

17. Which of the following roles do you have as a care partner?

Please select all the apply.

- a. Assisting with personal care (e.g., helping 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 medications)
- f. Mobility assistance (e.g., helping them getting up from a chair, assisting with balance)
- g. Providing emotional support
- h. Organizing social engagement
- i. Transportation
- j. Home organization (e.g., cleaning and organizing the home)
- k. Handling a crisis or medical emergency
- l. Financial responsibilities
- m. Grocery shopping and errands
- n. Not sure
- o. Prefer not to answer

[BLOCK 2] Care partner experiences

The next question will ask you about the symptoms of the person with Parkinson's disease that you care for.

Multiple choice, multiple answer, required

18. Over the past month, has the person with Parkinson's disease suffered from any of the following symptoms?

Please select all the 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. Not sure
- h. Prefer not to answer

Care partner experiences of daily living – MDS-UPDRS Part II

Experiences of Daily Living

Instructions:

If you are filling out this questionnaire as a care partner, please fill out the questionnaire from the perspective of the person with Parkinson's that you care for.

You can seek the input of the person you care for as you fill out the questionnaire.

This questionnaire will ask you about the experiences of daily living of the person with Parkinson's.

There are 13 questions. We are trying to be thorough, and some of these questions may therefore not apply to the person with Parkinson's now or ever. If the person with Parkinson's does not have the problem, simply mark 0 for NO.

Please read each one carefully and read all answers before selecting the one that best applies to you.

We are interested in the person with Parkinson's average or usual function over the past week including today. Some patients can do things better at one time of the day than at others. However, only one answer is allowed for each question, so please mark the answer that best describes what the person with Parkinson's can do most of the time.

He or she may have other medical conditions besides Parkinson's disease. Do not worry about separating Parkinson's disease from other conditions. Just answer the question with your best response.

Use only 0, 1, 2, 3, 4 for answers, nothing else. Do not leave any blanks.

Multiple choice, single answer, required

19. Who is filling out this questionnaire (check the best answer):

- a. Caregiver
- b. Patient and Caregiver in equal proportion

Multiple choice, single answer, required

20. **Speech**

Over the past week, have you had problems with your speech?

0: Normal: Not at all (no problems).

1: Slight: My speech is soft, slurred or uneven, but it does not cause others to ask me to repeat myself.

2: Mild: My speech causes people to ask me to occasionally repeat myself, but not every day.

3: Moderate: My speech is unclear enough that others ask me to repeat myself every day even though most of my speech is understood.

4: Severe: Most or all of my speech cannot be understood.

Multiple choice, single answer, required

21. **Saliva and drooling**

Over the past week, have you usually had too much saliva during when you are awake or when you sleep?

- 0: Normal: Not at all (no problems).
- 1: Slight: I have too much saliva but do not drool.
- 2: Mild: I have some drooling during sleep, but none when I am awake.
- 3: Moderate: I have some drooling when I am awake, but I usually do not need tissues or a handkerchief.
- 4: Severe: I have so much drooling that I regularly need to use tissues or a handkerchief to protect my clothes.

Multiple choice, single answer, required

22. Chewing and swallowing

Over the past week, have you usually had problems swallowing pills or eating meals? Do you need your pills cut or crushed or your meals to be made soft, chopped, or blended to avoid choking?

- 0: Normal: No problems.
- 1: Slight: I am aware of slowness in my chewing or increased effort at swallowing, but I do not choke or need to have my food specially prepared.
- 2: Mild: I need to have my pills cut or my food specially prepared because of chewing or swallowing problems, but I have not choked over the past week.
- 3: Moderate: I choked at least once in the past week.
- 4: Severe: Because of chewing and swallowing problems, I need a feeding tube.

Multiple choice, single answer, required

23. Eating tasks

Over the past week, have you usually had troubles handling your food and using eating utensils? For example, do you have trouble handling foods or using forks, knives, spoons, chopsticks?

- 0: Normal: Not at all (no problems).
- 1: Slight: I am slow but do not need any help handling my food and have not had food spills while eating.
- 2: Mild: I am slow with my eating and have occasional food spills. I may need help with a few tasks such as cutting meat.
- 3: Moderate: I need help with many eating tasks, but I can manage some alone.
- 4: Severe: I need help for most or all eating tasks.

Multiple choice, single answer, required

24. Dressing

Over the past week, have you usually had problems dressing? For example, are you slow or do you need help with buttoning, using zippers, putting on or taking off your clothes or jewelry?

- 0: Normal: Not at all (no problems).
- 1: Slight: I am slow, but do not need help
- 2: Mild: I am slow and need help for a few dressing tasks (buttons, bracelets).
- 3: Moderate: I need help for many dressing tasks.
- 4: Severe: I need help for most or all dressing tasks.

Multiple choice, single answer, required

25. Hygiene

Over the past week, have you usually been slow or do you need help with washing, bathing, shaving, brushing teeth, combing your hair, or with other personal hygiene?

- 0: Normal: Not at all (no problems).
- 1: Slight: I am slow, but I do not need help.
- 2: Mild: I need someone else to help me with some hygiene tasks.
- 3: Moderate: I need help for many hygiene tasks.
- 4: Severe: I need help for most or all my hygiene tasks.

Multiple choice, single answer, required

26. Handwriting

Over the past week, have people usually had trouble reading your handwriting?

- 0: Normal: Not at all (no problems).
- 1: Slight: My writing is slow, clumsy or uneven, but all words are clear.
- 2: Mild: Some words are unclear and difficult to read.
- 3: Moderate: Many words are unclear and difficult to read.
- 4: Severe: Most or all words cannot be read.

Multiple choice, single answer, required

27. Doing hobbies and other activities

Over the past week, have you usually had trouble doing your hobbies or other things you like to do?

- 0: Normal: Not at all (no problems).
- 1: Slight: I am a bit slow but do these activities easily.
- 2: Mild: I have some difficulty doing these activities.
- 3: Moderate: I have major problems doing these activities, but still do most.
- 4: Severe: I am unable to do most or all of these activities.

Multiple choice, single answer, required

28. Turning in bed

Over the past week, do you usually have trouble turning over in bed?

- 0: Normal: Not at all (no problems).
- 1: Slight: I have a bit of trouble turning, but I do not need any help.
- 2: Mild: I have a lot of trouble turning and need occasional help from someone else.
- 3: Moderate: To turn over I often need help from someone else.
- 4: Severe: I am unable to turn over without help from someone else.

Multiple choice, single answer, required

29. Tremor

Over the past week, have you usually had shaking or tremor?

- 0: Normal: Not at all. I have no shaking or tremor.
- 1: Slight: Shaking or tremor occurs but does not cause problems with any activities.
- 2: Mild: Shaking or tremor causes problems with only a few activities.
- 3: Moderate: Shaking or tremor causes problems with many of my daily activities.
- 4: Severe: Shaking or tremor causes problems with most or all activities.

Multiple choice, single answer, required

30. Getting out of bed, a car, or a deep chair

Over the past week, have you usually had trouble getting out of bed, a car seat, or a deep chair?

- 0: Normal: Not at all (no problems).
- 1: Slight: I am slow or awkward, but I usually can do it on my first try.
- 2: Mild: I need more than one try to get up or need occasional help.
- 3: Moderate: I sometimes need help to get up, but most times I can still do it on my own.
- 4: Severe: I need help most or all of the time.

Multiple choice, single answer, required

31. Walking and balance

Over the past week, have you usually had problems with balance and walking?

- 0: Normal: Not at all (no problems).
- 1: Slight: I am slightly slow or may drag a leg. I never use a walking aid.
- 2: Mild: I occasionally use a walking aid, but I do not need help from another person.
- 3: Moderate: I usually walk using a walking aid (cane/walker) to walk safely without falling. However, I do not usually need the support from another person.
- 4: Severe: I usually use the support of another person to walk safely without falling.

Multiple choice, single answer, required

32. Freezing

Over the past week, on your usual day when walking, do you suddenly stop or freeze as if your feet are stuck on the floor?

- 0: Normal: Not at all (no problems).
- 1: Slight: I briefly freeze, but I can easily walk again. I do not need help from someone else or a walking aid (cane or walker) because of freezing.
- 2: Mild: I freeze and have trouble starting to walk again, but I do not need someone's help or a walking aid (cane or walker) because of freezing.
- 3: Moderate: When I freeze, I have a lot of trouble starting to walk again and, because of freezing, I sometimes need to use a walking aid or need someone else's help.
- 4: Severe: Because of freezing, most or all of the time, I need to use a walking aid or someone's help.

This completes the questionnaire. We may have asked about problems you do not even have, and may have mentioned problems that you may never develop at all. Not all people develop all these problems, but because they can occur, it is important to ask all the questions to every person. Thank you for your time and attention in completing this questionnaire.

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[BLOCK 3] Care partner work impact

The following questionnaire asks about the effect of caregiving on your ability to work and perform regular activities.

Multiple choice, single answer, required

33. Are you currently employed (working for pay)?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Skip Logic: If (b.) No, (c.) Not sure or (d.) Prefer not to answer is selected, skip to “During the past seven days, how much did caregiving affect your ability to do your regular daily activities, other than work at a job?”

The next questions are about the **past seven days**, not including today.

Text entry, limited to digits between 0-200, required

34. During the past seven days, how many hours did you miss from work because of caregiving?
Include hours you missed on sick days, times you went in late, left early, etc., because of your caregiving responsibilities. Do not include time you missed to participate in this study.
_____ hours

Text entry, limited to digits between 0-200, required

35. During the past seven days, how many hours did you actually work?
_____ hours

Sliding scale, single answer, required

36. During the past seven days, how much did caregiving affect your productivity while you were working?

Think about days you were limited in the amount or kind of work you could do, days you accomplished less than you would like, or days you could not do your work as carefully as usual.

Consider only how much caregiving affected productivity while you were working.

If caregiving affected your work only a little, choose a low number. Choose a high number if caregiving affected your work a great deal.

Caregiving had
no effect on my
work

0 1 2 3 4 5 6 7 8 9 10

Caregiving
completely
prevented me
from working

Please select a number

Sliding scale, single answer, required

37. During the past seven days, how much did caregiving affect your ability to do your regular daily activities, other than work at a job?

By regular activities, we mean the usual activities you do, such as work around the house, shopping, childcare, exercising, studying, etc. Think about times you were limited in the amount or kind of activities you could do and times you accomplished less than you would like.

Consider only how much health problems affected your ability to do your regular daily activities, other than work at a job.

If caregiving affected your activities only a little, choose a low number. Choose a high number if caregiving affected your activities a great deal.

Caregiving had
no effect on my
daily activities

0 1 2 3 4 5 6 7 8 9 10

Caregiving
completely
prevented me
from doing my
daily activities

Please select a number

Multiple choice, single answer, required

38. Did you stop your paid job, or did you retire early because of your caregiving responsibilities for the person with Parkinson's?
- a. Yes
 - b. No
 - c. I am currently not employed for pay
 - d. Not sure
 - e. Prefer not to answer

[BLOCK 4] Care partner burden (Zarit-Burden Interview)

Matrix, multiple answer, single answer required per row

The following questions refer to the person with Parkinson's as your *relative*. Even if they are not your relative, please still answer the questions.

39. The following is a list of statements which reflect how people sometimes feel when taking care of another person.

After each statement, indicate how often you feel that way; never, rarely, sometimes, quite frequently, or nearly always.

There are no right or wrong answers.

| | a. Never | b. Rarely | c. Sometimes | d. Quite frequently | e. Nearly always |
|--|-----------------------|-----------------------|-----------------------|----------------------------|-------------------------|
| Do you feel that your relative asks for more help than he/she needs? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Do you feel that, because of the time you spend with your relative, you don't have enough time for yourself? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Do you feel embarrassed about your relative's behavior? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Do you feel angry when you are around your relative? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Do you feel that your relative currently affects your relationship with other family members? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

| | | | | | |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Are you afraid about what the future holds for your relative? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Do you feel that your relative is dependent upon you? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Do you feel strained when you are around your relative? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Do you feel that your health has suffered because of your involvement with your relative? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Do you feel that you don't have as much privacy as you would like, because of your relative? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Do you feel that your social life has suffered because you are caring for your relative? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Do you feel uncomfortable having your friends over because of your relative? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Do you feel that your | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

| | | | | | |
|---|---|---|---|---|---|
| relative seems to expect you to take care of him or her, as if you were the only one, he or she could depend on? | | | | | |
| Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses? | ○ | ○ | ○ | ○ | ○ |
| Do you feel that you will be unable to take care of your relative much longer? | ○ | ○ | ○ | ○ | ○ |
| Do you feel that you have lost control of your life since your relative's illness? | ○ | ○ | ○ | ○ | ○ |
| Do you wish that you could just leave the care of your relative to someone else? | ○ | ○ | ○ | ○ | ○ |
| Do you feel uncertain about what to do about your relative? | ○ | ○ | ○ | ○ | ○ |
| Do you feel that you should be doing more for your relative? | ○ | ○ | ○ | ○ | ○ |

| | | | | | |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Do you feel that you could do a better job in caring for your relative? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|

Matrix, multiple answer, single answer required per row

40. The next question asks how you feel overall.

| | a. Not at all (0) | b. A little (1) | c. Moderately (2) | d. Quite a bit (3) | e. Extremely (4) |
|--|--------------------------|------------------------|--------------------------|---------------------------|-------------------------|
| Overall, how burdened do you feel in caring for your relative? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Sliding scale, single answer, required

41. On a rating scale from 0 to 10 (0 being no impact and 10 being the highest impact), how big do you perceive the impact of being a care partner on your social life (i.e., lack of social interactions, not having time to yourself, dependence of a person with Parkinson's on you)?

Impact:

1 2 3 4 5 6 7 8 9 10

[BLOCK 5] Care partner coping

Matrix, multiple answer, single answer required per row

42. The following questions ask about the ways you are coping **(right now)** with your role as a care partner to someone with Parkinson's.

Please answer each question based on what you are **currently** doing to cope.

| | a. I haven't been doing this at all (1) | b. A little bit (2) | c. A medium amount (3) | d. I've been doing this a lot (4) |
|---|--|----------------------------|-------------------------------|--|
| I've been turning to work or other activities to take my mind off things. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been concentrating my efforts on doing something about the situation I'm in. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been saying to myself "this isn't real". | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been using alcohol or other drugs to make myself feel better. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been getting emotional support from others. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been giving up trying to deal with it. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been taking action to try to make the situation better. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been refusing to believe that it has happened. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been saying things to let my | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

| | | | | |
|--|---|---|---|---|
| unpleasant feelings escape. | | | | |
| I've been getting help and advice from other people. | ○ | ○ | ○ | ○ |
| I've been using alcohol or other drugs to help me get through it. | ○ | ○ | ○ | ○ |
| I've been trying to see it in a different light, to make it seem more positive. | ○ | ○ | ○ | ○ |
| I've been criticizing myself. | ○ | ○ | ○ | ○ |
| I've been trying to come up with a strategy about what to do. | ○ | ○ | ○ | ○ |
| I've been getting comfort and understanding from someone. | ○ | ○ | ○ | ○ |
| I've been giving up the attempt to cope. | ○ | ○ | ○ | ○ |
| I've been looking for something good in what is happening. | ○ | ○ | ○ | ○ |
| I've been making jokes about it. | ○ | ○ | ○ | ○ |
| I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping. | ○ | ○ | ○ | ○ |
| I've been accepting the reality of the fact | ○ | ○ | ○ | ○ |

| | | | | |
|---|-----------------------|-----------------------|-----------------------|-----------------------|
| that is has happened. | | | | |
| I've been expressing my negative feelings. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been trying to find comfort in my religion or spiritual beliefs. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been trying to get advice from other people about what to do. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been learning to live with it. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been thinking hard about what steps to take. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been blaming myself for things that happened. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been praying or meditating. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been making fun of the situation. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been exercising or doing sports. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been visiting support groups. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been visiting a therapist. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Matrix, multiple answer, single answer required per row

43. How effective do you perceive this coping strategy to be?

| | a. Not effective (1) | b. Somewhat effective (2) | c. Very effective (3) |
|---|-----------------------------|----------------------------------|------------------------------|
| I've been turning to work or other activities to take my mind off things. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been concentrating my efforts on doing something about the situation I'm in. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been saying to myself "this isn't real". | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

| | | | |
|--|-----------------------|-----------------------|-----------------------|
| I've been using alcohol or other drugs to make myself feel better. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been getting emotional support from others. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been giving up trying to deal with it. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been taking action to try to make the situation better. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been refusing to believe that it has happened. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been saying things to let my unpleasant feelings escape. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been getting help and advice from other people. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been using alcohol or other drugs to help me get through it. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been trying to see it in a different light, to make it seem more positive. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been criticizing myself. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been trying to come up with a strategy about what to do. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been getting comfort and understanding from someone. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been giving up the attempt to cope. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been looking for something good in what is happening. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been making jokes about it. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been accepting the reality of the fact that it has happened. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been expressing my negative feelings. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been trying to find comfort in my religion or spiritual beliefs. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been trying to get advice from other people about what to do. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been learning to live with it. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been thinking hard about what steps to take. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been blaming myself for things that happened. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been praying or meditating. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been making fun of the situation. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been exercising or doing sports. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been visiting support groups. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've been visiting a therapist. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Display Logic: If (b.), (c.) or (d.) is selected for corresponding question in first matrix

[BLOCK 6] Care partner needs

We would like to know what unmet needs you have had IN THE LAST MONTH as a result of supporting someone who has or had Parkinson's disease. An **unmet need** is a need that you have not been able to satisfy.

For each question, select the option that best describes your level of unmet need IN THE LAST MONTH. Please answer each question, even if you feel like there is no way to solve the problem.

Need not applicable - This was not a problem for me as a result of supporting someone with Parkinson's

Low unmet need - I needed a small amount of help with this issue but was not able to get it.

Moderate unmet need - I needed a moderate amount of help with this issue but was not able to get it.

High unmet need - I needed a high amount of help with this issue but was not able to get it.

Very high unmet need - I needed a very high amount of help with this issue but was not able to get it.

We know that your unmet needs may change over time. In this questionnaire, we want to know only about the unmet needs you have had IN THE LAST MONTH.

Matrix, multiple answer, single answer required per row

44. Unmet Information Needs

This part of the survey is about unmet needs that relate to finding information IN THE LAST MONTH.

For each statement, select the choice that best describes your level of unmet need.

| | a. Need not applicable (0) | b. Low Unmet Need (1) | c. Moderate Unmet Need (2) | d. High Unmet Need (3) | e. Very High Unmet Need (4) |
|---|-----------------------------------|------------------------------|-----------------------------------|-------------------------------|------------------------------------|
| Finding information about how to manage the illness at home | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Finding information about Parkinson's and its impact on sexual relationships | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Being able to talk openly about my feelings or worries with health care professionals | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Finding information about complementary or alternative therapies | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Finding information about the long-term side effects of treatments and medicines | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Knowing how to speak openly about Parkinson's | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

| | | | | | |
|---------------------------|--|--|--|--|--|
| with the person I support | | | | | |
|---------------------------|--|--|--|--|--|

Matrix, multiple answer, single answer required per row

45. **The Future**

This part of the survey is about unmet needs IN THE LAST MONTH that relate to knowing about the future.

For each statement, select the choice that best describes your level of unmet need.

| | a. Need not applicable (0) | b. Low Unmet Need (1) | c. Moderate Unmet Need (2) | d. High Unmet Need (3) | e. Very High Unmet Need (4) |
|--|-----------------------------------|------------------------------|-----------------------------------|-------------------------------|------------------------------------|
| Dealing with worry about Parkinson's getting worse | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Dealing with not knowing what lies in the future | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Matrix, multiple answer, single answer required per row

46. **Unmet Work and Financial Needs**

This part of the survey is about your unmet needs that relate to your job and finances IN THE LAST MONTH.

For each statement, select the choice that best describes your level of unmet need.

| | a. Need not applicable (0) | b. Low Unmet Need (1) | c. Moderate Unmet Need (2) | d. High Unmet Need (3) | e. Very High Unmet Need (4) |
|--|-----------------------------------|------------------------------|-----------------------------------|-------------------------------|------------------------------------|
| Getting my boss to be more supportive and understanding | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Being able to keep working | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Paying non-medical costs (such as travel, special foods) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Dealing with the way co- | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

| | | | | | |
|------------------------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| workers feel about my situation | | | | | |
| Finding and getting financial help | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Matrix, multiple answer, single answer required per row

47. Unmet Needs for Access and Continuity of Care

This part of the survey is about your unmet needs that relate to medical care IN THE LAST MONTH.

For each statement, select the choice that best describes your level of unmet need.

| | a. Need not applicable (0) | b. Low Unmet Need (1) | c. Moderate Unmet Need (2) | d. High Unmet Need (3) | e. Very High Unmet Need (4) |
|--|-----------------------------------|------------------------------|-----------------------------------|-------------------------------|------------------------------------|
| Having access to a variety of health care services and providers (dietitians, physiotherapists, occupational therapists) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Getting appointments with health care providers quickly enough | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Making sure the person I support could see the same health care professional at each follow-up visit | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Having enough time with the doctor | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Getting test results for the person I support quickly enough | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Having an ongoing case manager | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Matrix, multiple answer, single answer required per row

48. Unmet Personal and Emotional Needs

This part of the survey is about unmet needs that relate to you personally IN THE LAST MONTH.

For each statement, select the choice that best describes your level of unmet need.

| | a. Need not applicable (0) | b. Low Unmet Need (1) | c. Moderate Unmet Need (2) | d. High Unmet Need (3) | e. Very High Unmet Need (4) |
|--|-----------------------------------|------------------------------|-----------------------------------|-------------------------------|------------------------------------|
| Not sleeping well | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Dealing with feeling stressed | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Dealing with worries about the emotional well-being of your family | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Working around the house (cooking, cleaning, home repairs, etc.) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Help to reduce the time burden of caring | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Assistance with physical care | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Ability to attend to my own health needs | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Maintaining social relationships | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

For each statement, select the choice that best describes your level of unmet need.

| | a. Need not applicable (0) | b. Low Unmet Need (1) | c. Moderate Unmet Need (2) | d. High Unmet Need (3) | e. Very High Unmet Need (4) |
|---|-----------------------------------|------------------------------|-----------------------------------|-------------------------------|------------------------------------|
| Knowing that I am doing the best I can | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Dealing with feeling like I'm letting the person I support down | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Finding meaning in this experience | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Discussing feelings with other care partners | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Dealing with changes in the relationship with the person I care for | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |