

PARKINSON'S CARE PARTNER SURVEY



RESULTS REPORT

#PDCare

Overview

In April 2022, Kyowa Kirin partnered with the Davis Phinney Foundation for Parkinson's and the Parkinson's and Movement Disorder Alliance on research to better understand the unique challenges of those caring for loved ones with Parkinson's disease.

The 2022 Parkinson's Care Partner Survey focuses on the care partner experience, disease education/knowledge, relationship with their healthcare team, and resources/overall support to highlight aspects of the care partner role that can be critical to the overall Parkinson's patient journey.

This presentation summarizes the key findings of the research and includes additional survey data and demographics in the appendix.

Goals and methodology

Goals

Gain a better understanding of the experiences of the Parkinson's Disease care partner specifically:

- Understand the challenges of caring for the PD patient
- Gain insights into care partner communications with the PD care team and how/when they are facilitated
- Evaluate the care partner's knowledge — specifically with how it relates to “OFF” symptoms
- Understand the impact of “OFF” symptoms on care partners' lives
- Gain insights into helpful care partner resources to provide support and help facilitate productive conversations

Methodology

A survey of a total of 752 American Care Partners of Patients with Parkinson's Disease via online and computer-assisted telephone interviewing (CATI) from 28th February to 22nd March 2022.

Population	Sample	Margin of Error*
American Care Partners of Patients with Parkinson's Disease Age 18+	752	± 3.574%

* At the 95% confidence level

Summary of demographics and primary caregiving duties

Family role:

10%

children of
a patient

82%

spouses or
significant others

Age:

64.8 years

average age of
care partners

58 years

mean start
age

Caregiving Scope:

Been a care partner
for an average of
6.8 years

Spend an **average of
46.7 total hours/week**
on caregiving

93% said their primary responsibility as a care partner is to provide emotional support

87% said they participate in discussions with the healthcare team

80% said they manage doctor's appointments, advocate for the person's care and provide transportation for appointments

Related Survey Questions:

- S2. What is your relationship to the person you care for with Parkinson's Disease? The person with Parkinson's Disease is ...
- S4. How long have you been caring for someone with Parkinson's Disease?
- S5. In an average week, how many total hours do you spend doing specific tasks related to caring for someone with Parkinson's Disease?
- S6. What is your birth month and year?
- Q16: What are your primary responsibilities as a care partner for someone with Parkinson's Disease?

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CARE PARTNER
SURVEY**

 YOWA KIRIN

 PMD Alliance
Parkinson & Movement Disorder Alliance

 DAVIS PHINNEY
Pharmaceuticals for Parkinson's

Categories of key findings



Caregiving Challenges and Impact



Communications with the Patient and Healthcare Team



Resources and Disease Education



Key findings illustrate the depth of care partner challenges



Top five challenges

73%

watching the patient's symptoms worsen

54%

finding time to take care of themselves

48%

addressing their own fears and anxieties

42%

finding time to balance their personal or social life

41%

feeling alone/
not having enough support

Related Survey Question:

Q18. Which, if any, of the following are the MAIN challenges you face as a Care Partner for someone with Parkinson's Disease? Additional challenges survey respondents could choose which weren't noted above include: communication, disease understanding, financial barriers, new treatment/therapies and access to resources.

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How respondents expressed top caregiving challenges



““ *While PD itself is challenging, I find that the dementia is the most stressful thing about living with & caring for my husband. He is a different person now & not an easy one (like he used to be) ...I'm mentally & emotionally exhausted. We don't have the finances for a facility, so this is how it will be.”*

““ *Having to do EVERYTHING myself! All of his care, all of the car maintenance, all of the yard work, all of the house maintenance, all of the finances, the taxes, all of the doctor scheduling, all of the prescription refilling, all of the medication administration, all of the meal prep, all of the shopping, all of the house cleaning. AND having NOONE to even talk to!!! It's killing me. Really.”*

““ *Watching my husband slowly disappear.”*

““ *Keeping relationship as spouse from being lost in caregiving.”*

““ *Seeing a vibrant man forget his words. His thoughts and his purpose. Retirement was not supposed to look like this. The changes in his mind make him cry and be scared. He is a different version of himself...”*

““ *Watching his strength and confidence fail. Keeping his depression at bay. Helping him accept his diagnosis. Maintaining his quality of life.”*

Related Survey Question:

Q17. *What has been the most challenging responsibility or activity for you as a care partner of someone with Parkinson's Disease?*

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The longer a person is a care partner, the greater the impact it has on their health and well-being



Respondents report caring for someone with Parkinson's disease had a somewhat negative or negative impact on their...



Percentage of respondents who reported a somewhat negative or negative impact, broken out by the number of years of caregiving.

Related Survey Question:

Q19. What impact has caring for someone with Parkinson's Disease had on each of the following aspects of your life?

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Digging deeper into the negative impacts on Parkinson's care partners



Rewarding, Isolating and Exhausting

77% said being a care partner had strengthened their relationship with the person with Parkinson's

YET

75% have had a difficult time adjusting to life as a care partner

AND

82% agreed that caregiving made them feel lonely sometimes

AND

81% said that caring for someone with Parkinson's was the hardest thing they'd ever done

“*My emotional health as well mental health was negatively impacted due to high stress of caregiving responsibilities which resulted in depression, fatigue and social isolation.*”

“*The grief I feel associated with losing the man I love. The lack of communication. The feeling of aloneness.*”

“*I'm all alone in this, for all these years, I have been alone and it feels really bad at times.*”

“*Not having help or aides or time for and by myself it's a 24 hour a day job.*”

Related Survey Questions:

Q20. How much do you agree with each of the following statements?

Q17. What has been the most challenging responsibility or activity for you as a care partner of someone with Parkinson's Disease?

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Digging deeper into the negative impacts on Parkinson's care partners *(continued)*



Limits to Self Care

- 74%** agreed that it was hard to find time to exercise and eat healthy
- 55%** feel guilt about asking for help from others or taking breaks from being a care partner
- 47%** said they do not regularly take time for themselves

“ How to care for me -- an ongoing battle. I get depressed, feel unappreciated, have no time to myself etc. I do not worry about caring for my husband.”

“ I'm tired of doing EVERYTHING. Literally no help possible from him. it's like having another small child. & no way to get a BREAK. I feel trapped.”

“ Losing myself and my time to do what I would like to do. Daily activities take a great deal of time. Also, I tire easily from the constant being on for most of the day.”

Related Survey Questions:

Q20. How much do you agree with each of the following statements?

Q17. What has been the most challenging responsibility or activity for you as a care partner of someone with Parkinson's Disease?

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Digging deeper into the negative impacts on Parkinson's care partners *(continued)*



Life Interrupted

“OFF” episodes have resulted in

58% canceled/changed plans

54% unable to sleep or have their sleep interrupted

48% had to leave an event or social gathering early



When my partner goes “OFF” unexpectedly and needs my help performing a personal task or household chore that takes me away from my own work and activities.”



Unpredictability of PWP to care for herself or to need assistance. Therefore, I am ON CALL 24/7 whether I'm needed for a task or not.”



It was the occurrence of the Off Episodes, as they would not only exhaust me emotionally, but they made it difficult for me to understand my husband with each episode.”



I've had to cancel or change arrangements, and I've even had to leave gatherings in the middle of them, which has had a bad impact on my social life.”

Related Survey Questions:

Q22. Which, if any, of the following scenarios have you experienced because of an “OFF” episode?

Q17. What has been the most challenging responsibility or activity for you as a care partner of someone with Parkinson's Disease?

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Care partners are knowledgeable about “OFF” episodes and PD symptoms, but there is still room for improvement



Knowledge of PD symptoms and understanding of OFF episodes

91% said they are at least somewhat knowledgeable about “OFF” episodes

BUT → **15%** were not able to correctly identify an “OFF” episode

88% stated that they often recognize new symptoms before the patient does

AND → **85%** said that the patient was not always aware they are experiencing symptoms

76% said that the patient was not always aware of having an “OFF” episode

82% said they were least knowledgeable about the latest advancements in treatments/therapies

Related Survey Questions:

Q1. Please describe your level of knowledge about the following aspects of Parkinson’s Disease.

Q4. To your knowledge, what best describes “OFF” episodes/periods/time?

Q7. How much do you agree with each of the following statements?

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Care partners are less proactive in discussing symptoms and managing care with the healthcare team



Overall Communication with Healthcare Team

Frequency of Care Partner and Healthcare Team Communications

- 33%** initiate quarterly calls
- 30%** initiate monthly calls
- 12%** initiate weekly calls
- 23%** never initiate calls

Top three reasons for scheduling a Healthcare Team visit

- 73%** said ongoing management/check-ins with the Healthcare Team
- 62%** said new or worsening motor symptoms
- 57%** said new or worsening non-motor symptoms

To prepare for the Healthcare Team visit

- 79%** make a list of questions
- 78%** discuss the latest symptoms
- 45%** maintain a symptom diary or tracker
- 29%** talk to other people in Parkinson's community

Related Survey Questions:

Q12. How often do you, as a care partner, initiate a call with the healthcare team?

Q13. What leads to you scheduling a Healthcare Team visit?

Q14. How do you and your loved one living with Parkinson's Disease prepare for Healthcare Team visits?

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Care partners participate in healthcare team meetings but may need more lay-person explanations to understand symptoms and managing care



Discussing Symptoms

61% talk to the patient very often about their symptoms.

YET

42% talk to their Healthcare Team very often about their patients' symptoms

49% sometimes talk to the Healthcare Team about their patients' symptoms

“Despite the fact that I engage in all meetings with the healthcare team, I often find myself unable to comprehend the majority of what is said when physicians discuss topics such as Parkinson's disease progression or new symptoms that may develop in the future.”

“As I am a healthcare advocate for my husband during appointments with the doctors, I find it hard to understand the medical terms they use during explanation about Parkinson's.”

Related Survey Questions:

Q10. How often do you talk to the person you are caring for about his or her Parkinson's Disease symptoms?

Q11. How often do you talk to the Healthcare Team (e.g., Doctors, Physician Assistants, APRNs/Nurse Practitioners, etc.) about the symptoms of Parkinson's Disease the person you are caring for are experiencing?

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Care partners rely on the healthcare team and their peers as top resources but seek more support for every aspect of the role



Top three preferred resources

- 49%** the healthcare team and care partner support groups
- 40%** Online or in-person seminars
- 34%** Disease education materials & resources provided by Parkinson's advocacy groups

Education needs identified

- “Someone to explain where the patient currently is in this disease. What to expect next. What help is available.”
- “There should be guides ...that can help the caregivers to tackle the person in different stages of the disease.”
- “I need a guide for home caregivers like myself that quickly discusses how we might provide care in the absence of a professional caregiver.”
- “Tools for medicine management as the number of pills taken per day are high and patient or caregiver might miss some of the medications.”

Related Survey Question:

Q25. What, if any, of the following are your top three preferred activities/resources for helping you manage being a care partner to someone with Parkinson's Disease?

Q24. What resources do you need that you do not currently have to help you care for someone with Parkinson's Disease?

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Care partner needs: emotional support



“*Would like to be able to speak to someone 24 hours a day for those times that seem unbearable.*”

“*Mental health support for both myself and my sibling with Parkinson's.*”

“*Counseling on how to handle his stubbornness in giving up control and asking for help.*”

“*Adequate mental and emotional health support for myself as a person, not just “coping mechanisms” and support geared toward solely the caregiver role. Loss and grief support.*”

“*On call mentors, kind of like AA, would be nice*”

Related Survey Question:

Q24. *What resources do you need that you do not currently have to help you care for someone with Parkinson's Disease?*

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Care partner needs: financial support



“Insurance-paid professional caregiver to give me time off. All help is now is out of pocket.”

“Spread of awareness about financial patient assisted programs.”

“Training programs designed to teach caregivers on how to properly manage their finances.”

“Someone to help me understand and manage the long-term care insurance.”

“Money to hire a respite caregiver or housecleaner.”

Related Survey Question:

Q24. What resources do you need that you do not currently have to help you care for someone with Parkinson's Disease?

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Care partner needs: care navigation and support services



- “Community-based resources for recreational, avocational group activities for socialization.”
- “More updates on where research is heading.”
- “Activities in our small community that would offer social and exercise groups for people with Parkinson’s and their caregivers for support.”

- “A Navigator or Care Coordinator would be helpful. Someone to check in with related to symptoms or questions that may come up between scheduled visits with Neurologist. Help with comorbidities.”
- “Transportation. I do not drive and it’s expensive to get a cab/Uber to take us to Phoenix 1.75 hrs. away where my husband has to go for specialists.”

Related Survey Question:

Q24. What resources do you need that you do not currently have to help you care for someone with Parkinson’s Disease?

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Care partner needs: respite care



“Respite care on a regular basis in order to make sure work, grocery shopping and other appointments do not leave them home alone too long.”

“Information on where / how to access palliative care and respite care.”

“A place where I can send my husband to for a few days or someone who can take care of him for a few days. So, I can get away to recharge.”

“Information on respite care so I can get a break, in-home health services, transportation assistance.”

Related Survey Question:

Q24. What resources do you need that you do not currently have to help you care for someone with Parkinson's Disease?

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Care partner needs: peer support



“Talking with other caregivers. Understanding what I should and should not be doing to help”

“Online support group. People going through the same experience as me in dealing with the disease”

“A support group of caregivers close by.”

“Caregivers’ forums to ask our doubts and connect with other caregivers and become a part of network of support.”

Related Survey Question:

Q24. What resources do you need that you do not currently have to help you care for someone with Parkinson’s Disease?

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Additional Survey Data & Demographics

Knowledge of Parkinson's Disease and Recognition of Symptoms

How confident are you in recognizing each of the following motor symptoms in the person you care for?

Over 90% were confident in recognizing tremor, speech changes/problems, postural instability, rigid muscles, bradykinesia and loss of automatic movements

While

86% were confident in recognizing writing changes

How confident are you in recognizing each of the following non-motor symptoms in the person you care for?

Over 80% were confident in recognizing speech problems, sleep problems/fatigue, mood disturbances, cognitive problems, apathy, hallucinations and delusions, and constipation

While

76-77% were confident in recognizing hyposomnia and light-headedness

**% who answered Very confident or Somewhat confident*

Knowledge of Parkinson's Disease and Recognition of Symptoms

“OFF” time is when medication for Parkinson’s Disease is not working optimally, and symptoms return. How confident are you in recognizing an “OFF” episode in the person you care for?

42%
Very confident

48%
Somewhat confident

10%
Not confident at all

Has the person you care for ever experienced “OFF” time?

75%
Yes

14%
No

11%
I don't know

Knowledge of Parkinson's Disease and Recognition of Symptoms

Parkinson's disease is a neurological condition that affects signals in the brain related to movement.

How familiar are you with each of the following types of neurotransmitters and neuromodulators associated with Parkinson's Disease?

	Adenosine	Dopamine	Gamma-Aminobutyric Acid	Glutamate	Norepinephrine	Serotonin
% Familiar*	28%	95%	35%	30%	42%	69%
Very familiar	5%	53%	10%	5%	9%	24%
Somewhat familiar	23%	42%	25%	25%	33%	45%
Not familiar at all	72%	5%	65%	70%	58%	31%

If response is Very Familiar/Somewhat Familiar: How did you learn about the role of these neuropathways?

Treating Physician	61%	57%	63%	61%	59%	54%
Healthcare Team	53%	41%	55%	54%	45%	38%
Advocacy Group Website or Program	40%	41%	41%	44%	44%	45%
General Parkinson's Disease speaker events or classes	40%	42%	44%	45%	46%	46%
Care Partner Support Group	38%	31%	38%	37%	36%	28%
Live Social Group Events	12%	9%	15%	14%	11%	9%
None of the Above	13%	11%	11%	12%	12%	13%

Resources and Knowledge

What type of resources would be helpful to prepare for a healthcare team visit?

- 70%** Doctor – patient discussion guide
- 57%** Symptom diary/tracker (printable, journal)
- 39%** Symptom diary/tracker (mobile app, online)
- 5%** Other
- 8%** None

How do you learn about new Parkinson's Disease research and treatment options?

- 59%** Treating physician
- 45%** Advocacy Group website or program
- 42%** Healthcare team (e.g., Nurse, Physician Assistant, etc.)
- 38%** General PD speaker events or classes / care partner support group / personal internet search
- 21%** News websites
- 11%** Live social group events
- 4%** Advertising / Other
- 2%** None of the above

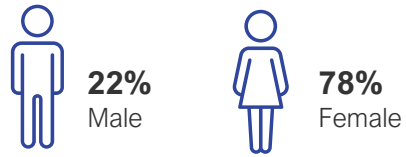
Caregiving Impact and Challenges

What, if any of the following, causes you the greatest concern as a care partner for someone with Parkinson's disease?

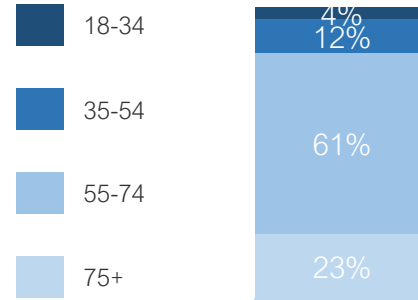


Demographic data

GENDER



AGE



RELATIONSHIP TO PATIENT

Family (Net)	98%
My Spouse/Significant Other	82%
My Parent	10%
My Grandparent	3%
Another Family Member	3%
My Child	0%
My Friend	1%
Neighbour	0%
Other	1%

RECOGNITION OF CARE PARTNER ROLE

Before he or she was diagnosed with Parkinson's Disease	25%
At the time of diagnosis	28%
When his or her Parkinson's Disease started to progress	45%
When a previous Care Partner was no longer able to provide care	1%

YEARS OF PARKINSON'S DISEASE CAREGIVING (NET)

1 Year or less	9%
Between 2 and 3 years now	22%
Between 4 and 5 years now	21%
Between 6 and 10 years now	31%
11 Years or more	17%

MARITAL STATUS

Married	87%
Single	6%
Divorced	1%
Separated	0%
Domestic/Registered Partnership	4%
Civil Union	0%
Widow/widower	1%
Prefer not to answer	1%

TIME SPENT CARE - NET (Average weekly hours/week)

7 Hours a week or less	13%
8 to 14 Hours a week	9%
15 to 21 Hours a week	11%
22 to 28 Hours a week	6%
29 to 35 Hours a week	8%
36 to 42 Hours a week	6%
43 to 48 Hours a week	2%
49 Hours a week or more	44%

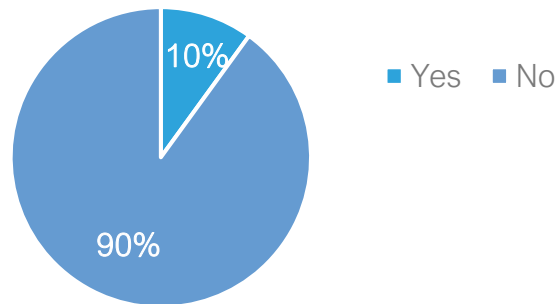
Base: Total (n=752)

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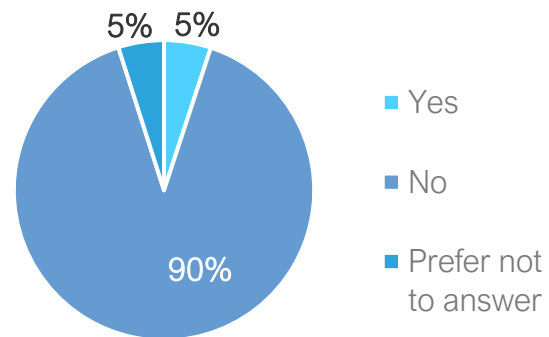
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Demographic data (cont'd)

CHILDREN UNDER 18 LIVING IN THE HOUSEHOLD



ETHNICITY



HOUSEHOLD INCOME

Less than \$35,000 (Net)	17%
\$35,000-\$49,999	13%
\$50,000-\$74,999	18%
\$75,000-\$99,999	13%
Over \$100,000 or more	18%
Prefer not to answer	21%

RACE

White	92%
Black or African American	2%
Asian or Asian Indian	1%
American Indian or Alaska Native	1%
Other	1%
Prefer not to answer	3%

Base: Total (n=752)

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