



The Financial and Social Impact of Parkinson's Disease and Parkinson's Related Disorders

April 1, 2025



Survey Overview

Parkinson's disease (PD) and Parkinson's related disorders (PRD) (e.g., dementia with Lewy bodies (DLB), progressive supranuclear palsy (PSP), multiple system atrophy (MSA), corticobasal degeneration/syndrome (CBD/S), vascular parkinsonism) can put financial and social costs on patients and their families. To better understand these costs, The Michael J. Fox Foundation, the Parkinson's Foundation, the American Parkinson Disease Association and CurePSP have partnered with researchers at the Lewin Group to develop an important survey. Your answers will help paint a clearer picture of the financial burden that people and families experience because of Parkinson's disease and PRD. Please note that participation in this survey is voluntary.

The results will be used in discussions with lawmakers and others to advocate for policies to improve the lives of people with Parkinson's or PRD and their families.

You should take this survey if:

- You or someone in your family has Parkinson's disease or a related disorder,
OR
- Someone in your family had Parkinson's disease or related disorders and passed away within the last 12 months,
AND
- You are familiar with your family's finances,
- You know your family's Parkinson's health care needs

You may also find it helpful to have other documents handy when completing this survey, such as tax returns, insurance statements, and medical bills.

The survey should take no more than forty (40) minutes to complete. Please try your best to answer all the questions. If you are not sure about a question, your best estimate is fine.

Thank you for taking part in this important survey!



Section A: Health Status

This section asks about the health of the person with Parkinson's disease (PD) or Parkinson's related disorders (PRD).

Your doctor or care provider may have used the following terms for your condition, which are considered Parkinson's related disorders for this survey:

- Atypical parkinsonism
- Dementia with Lewy bodies (DLB)
- Progressive supranuclear palsy (PSP)
- Multiple system atrophy (MSA)
- Corticobasal degeneration/syndrome (CBD/S)
- Vascular parkinsonism

In this survey, we use PWP/PRD to refer to a person with either Parkinson's disease or Parkinson's related disorders.

The survey also includes questions about the **unpaid care partners**; a care partner is considered "unpaid" even if they receive payment or reimbursement as a family caregiver from Medicaid or the Veterans Administration. If you are unsure about a specific question, please answer to the best of your knowledge.

Please note: If you were family or friends with a PWP/PRD who passed away in the past 12 months, please answer the questions as best you can based on your knowledge.

Multiple choice, single answer, required

1. Which of the following **best describes you** (the person who is responding to this survey)?
 - a) A person with Parkinson's disease or Parkinson's related disorder (PWP/PRD)
 - b) An unpaid care partner for someone who has Parkinson's disease/Parkinson's related disorders (PD/PRD)
 - c) An unpaid care partner for someone who had PD/PRD and passed away in the last 12 months
 - d) An unpaid care partner for someone who had PD/PRD and passed away more than 12 months ago
 - e) A family member to someone who has PD/PRD, but I do not identify as a care partner
 - f) A friend to someone who has PD/PRD, but I do not identify as a care partner
 - g) Do not have PD/PRD and do not know anyone with PD/PRD

Skip Logic: If (d.), (e.), (f.), or (g.) is selected, then skip to End of Survey Thank You 2

Multiple choice, single answer, required

2. Which of the following diagnoses best describes the person with Parkinson's Disease or a Parkinson's related disorder?



- a) Parkinson's Disease (PD)
- b) Dementia with Lewy Bodies (DLB)
- c) Progressive Supranuclear Palsy (PSP)
- d) Multiple System Atrophy (MSA)
- e) Corticobasal Degeneration/Syndrome (CBD/S)
- f) Vascular parkinsonism
- g) Parkinsonism otherwise not specified
- h) Another form of parkinsonism, please specify _____

Text entry, required

3. Please tell us when the PWP/PRD passed away. Please enter your best guess if you are not sure.

_____ (mm/yyyy)

Display logic: If (c. An unpaid care partner for someone who had PD/PRD and passed away in the last 12 months) is selected for "Which of the following **best describes you**"

Text entry, required

4. In which year were you, or the PWP/PRD you care for **first diagnosed** with the disease? Please use a four-digit numeric value for the year.

Matrix table, single answer per row, required

5. If you, or the PWP/PRD you care for has exhibited any of the symptoms/conditions below in the past 12 months, please select the appropriate box to indicate their severity, on average. When responding, please consider the following definitions:

Mild: Symptom/condition is occasional or sporadic, not keeping PWP/PRD from normal activities.

Moderate: The symptom/condition is usually present, some help/device is needed, and it occasionally keeps the PWP/PRD from normal activities.

Severe: PWP/PRD needs assistance to cope with problem. However, even with assistance, the PWP/PRD has difficulty participating in normal activities.

	Did not experience the symptom	Mild	Moderate	Severe
Slowed movement	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tremors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Poor balance and coordination	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Orthostatic hypotension (e.g., lightheaded or dizziness)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Trouble speaking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Trouble writing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Urinary issues such as urinary urgency or loss of bladder control	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gastrointestinal issues such as constipation or irritable bowel syndrome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sleep issues (such as trouble falling asleep, staying asleep, abnormal dreams, poor quality sleep, frequent awakenings during the night, sleepiness during the day due to trouble sleeping at night, excessive or sudden daytime sleepiness, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fatigue and loss of energy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty with concentrating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty with memorizing or recalling information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty with understanding requirements to complete complex tasks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Drooling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty with swallowing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vision problems (e.g., blurred vision or trouble reading)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain (e.g., muscle stiffness and pain, painful muscle spasm, joint pain, neuropathic pain)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anxiety	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Depression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Apathy (e.g., lack of interest or enthusiasm)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hallucinations or delusions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Falls resulting in injury	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



Multiple choice, single answer, required

6. In the past 12 months, did you, or the PWP/PRD you care for use any mobility **assistance devices** (e.g., walker, wheelchair, etc.) for reasons related to their medical condition?
- a) Yes
 - b) No
 - c) Don't know

Matrix table (dropdown), required

- a. To the best of your knowledge, approximately how many months (in the past 12 months) did you, or the PWP/PRD you care for use any of the following devices? Please round up partial months (e.g., if time spent was more than three but less than four months, please enter 4).

	Months relying on a walking device in the past 12 months
Walkers	_____
Wheelchairs	_____
Canes	_____
Scooters	_____

Display logic: If (a. Yes) is selected for “In the past 12 months, did you, or the PWP/PRD you care for use any mobility **assistance devices** (e.g., walker, wheelchair, etc.) for reasons related to their medical condition?”



Section B: Family Characteristics and Health Insurance Coverage

This section asks questions about the **demographic information** of the person with Parkinson's disease (PD) or Parkinson's related disorders (PRD), and the care partners.

Your doctor or care provider may have used the following terms for your condition, which are considered Parkinson's related disorders for this survey:

- Atypical parkinsonism
- Dementia with Lewy bodies (DLB)
- Progressive supranuclear palsy (PSP)
- Multiple system atrophy (MSA)
- Corticobasal degeneration/syndrome (CBD/S)
- Vascular parkinsonism

In this survey, we use PWP/PRD to refer to a person with either Parkinson's disease or Parkinson's related disorders.

The survey also includes questions about the **unpaid care partners**, a care partner is considered "unpaid" even if they receive payment or reimbursement as a family caregiver from Medicaid or the Veterans Administration. If you are unsure about a specific question, please answer to the best of your knowledge.

Unpaid care partners provide care or assistance to PWP/PRD to help them manage their disease. They may be family members, other relatives, friends or neighbors, and are not receiving payment for the care they provide. The **types of care provided** may include help with housework, home maintenance or outdoor activities; emotional support; transportation services including trips to the doctor or store; and assistance with meal preparation.

Unpaid care partners may also provide assistance with other activities of daily living (ADLs), including eating, bathing, dressing, toileting (being able to get on and off the toilet and perform personal hygiene functions), and transferring (being able to get in and out of bed or a chair). In this survey, these daily life related care and assistance **will be collectively referred to as either unpaid care or daily care.**

In answering the questions in this section, please refer to the individual who spends the most time providing unpaid care to the PWP/PRD as the **primary care partner**. Please refer to any individual who provides unpaid care to the PWP/PRD, but less frequently than the primary care partner, as the **non-primary care partner**.

As noted before, if the PWP/PRD in your family has passed away, please answer the questions as best you can based on his/her experience before passing away.

Multiple choice, single answer, required

7. Do you live in the United States?



- a) Yes
- b) No

Multiple choice, single answer, required

8. Where do you currently live?

- a) Urbanized area (at least 50,000 residents)
- b) Urban clusters/suburban areas (at least 2,500 residents, but fewer than 50,000 residents)
- c) Rural area (open country and settlements with fewer than 2,500 residents)
- d) Do not know

9. (PWP/PRD ONLY) Do you currently have **any type** of health insurance?

- a. Yes
- b. No
- c. Don't know

Display logic: If (a. A person with Parkinson's disease or Parkinson's related disorder) is selected for "Which of the following **best describes you**"

Matrix table, single answer, required

10. (PWP/PRD ONLY) What type of **insurance** do you currently have? *Check the appropriate box for each type of health insurance.*

	Yes	No	Don't Know
Commercial Insurance through Employer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Individual Commercial Insurance (Private)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medicaid/CHIP	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medicare Part A (Hospital Insurance)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medicare Part B (Medical Insurance)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medicare Part C (Medicare Advantage)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medicare Part D (Prescription Drug Coverage)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Military/CHAMPUS/TRICARE	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Display logic: If (a. Yes) is selected for "Do you currently have **any type** of health insurance?"

Dropdown, required

- a. (PWP/PRD ONLY) If you **do not currently have any health insurance coverage**, approximately how many months in the past 12 months have you been without coverage? Please round up partial months (e.g., if time spent was more than three but less than four months, please enter 4). _____

Display logic: If (b. No) is selected for "Do you currently have **any type** of health insurance?"

Matrix table, single answer, required



11. How many people, excluding paid professional caregivers, are in your, or the PWP/PRD you care for, household, **not** including the PWP/PRD?

	None	One	Two	Three	Four or More
Adults (age 18 and over)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Children (under age 18)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Multiple choice, single answer, required.

12. In the past 12 months, have you, or the PWP/PRD you care for, received care from at least one **unpaid care partner**? As a reminder, *unpaid care partners may still receive payment or reimbursement as a family caregiver from Medicaid or the Veterans Administration.*

- a. Yes
- b. No
- c. Not applicable

	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Matrix table, single answer, required

13. Please describe the relationship of the unpaid care partner(s) to the PWP/PRD in the table below. Please enter the number of care partners in each relationship category. Enter “0” if there are no care partners in that category.

	Spouse/ partner/ significant other	Parent	Child	Sibling	Friend	Other
Primary Care Partner(s) (the individual(s) who spent the most time providing unpaid care to the PWP/PRD)	_____	_____	_____	_____	_____	_____
Non-primary Care Partner(s) (the individual(s) who provides unpaid care to the PWP/PRD, but less frequently than the primary care partner)	_____	_____	_____	_____	_____	_____

Display logic: If (a. Yes) is selected for “In the past 12 months, have you, or the PWP/PRD you care for, received care from at least one **unpaid care partner**?”



Multiple choice, single answer, required

14. What is your or the PWP/PRD you care for **marital status**?

	Married/ Living with partner	Widowed	Divorced/ Separated	Never Married	Prefer not to answer	Don't know
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Multiple choice, single answer, required

15. What were your or the PWP/PRD you care for **total household earnings in the most recent tax year**?

This includes the amount received through wages, salary, commissions, overtime pay, or tips from all jobs before taxes or other deductions, and excludes any social security income, supplemental security income (SSI), or social security disability insurance (SSDI). **We recommend that you refer to last year's tax return.** The **household** includes all family members living with you and excludes co-residents who are financially independent and all paid care partners who are not family members.

Less than \$25,000	<input type="checkbox"/>
\$25,000 to less than \$50,000	<input type="checkbox"/>
\$50,000 to less than \$75,000	<input type="checkbox"/>
\$75,000 to less than \$100,000	<input type="checkbox"/>
\$100,000 to less than \$125,000	<input type="checkbox"/>
\$125,000 to less than \$150,000	<input type="checkbox"/>
\$150,000 to less than \$175,000	<input type="checkbox"/>
\$175,000 to less than \$200,000	<input type="checkbox"/>
More than \$200,000	<input type="checkbox"/>
Prefer not to answer	<input type="checkbox"/>





Section C: Financial Impact of Parkinson's Disease

This section asks questions about the Parkinson's disease (PD) **costs** that may impact the person with Parkinson's disease or Parkinson's related disorders, the care partners, and their family.

Your doctor or care provider may have used the following terms for your condition, which are considered Parkinson's related disorders for this survey:

- Atypical parkinsonism,
- Dementia with Lewy bodies (DLB)
- Progressive supranuclear palsy (PSP)
- Multiple system atrophy (MSA)
- Corticobasal degeneration/syndrome (CBD/S)
- Vascular parkinsonism

In this survey, we use PWP/PRD to refer to a person with either Parkinson's disease or Parkinson's related disorders.

The survey also includes questions about the **unpaid care partners**; a care partner is considered "unpaid" even if they receive payment or reimbursement as a family caregiver from Medicaid or the Veterans Administration. These financial impacts include expenses on things such as home modifications (e.g. building a ramp in place of steps to enter/exit home; building guard rails or to bath/shower area, etc.), car modifications, increased transportation due to seeking care, and any impact PD/PRD may have had on employment or other social activities. You may refer to additional resources (e.g. transportation receipts for traveling to and from doctor's appointments, etc.) to provide the most complete information.

Again, unpaid care partners provide care or assistance to PWP/PRD to help them manage their disease. They may be family members, other relatives, friends or neighbors, and are not receiving payment for the care they provide. The **types of care provided** may include help housework, home maintenance or outdoor activities; emotional support; transportation including trips to the doctor or store; and assistance with meal preparation.

Unpaid care partners may also provide assistance with other activities of daily living (ADLs), including eating, bathing, dressing, toileting (being able to get on and off the toilet and perform personal hygiene functions), and transferring (being able to get in and out of bed or a chair). In this survey, these daily life related care and assistance **will be collectively referred to as either unpaid care or daily care.**

In answering the questions in this section, please refer to the individual who spends the most time providing unpaid care to the PWP/PRD as the **primary care partner**. Please refer to the individual(s) who provides unpaid care to the PWP/PRD, but less frequently than the primary care partner, as the **Non-Primary Care Partner**.

As noted before, if the PWP/PRD in your family has passed away, please answer the questions as best you can based on his/her experience before passing away.



The following questions ask for details about **money spent** by the PWP/PRD's household and unpaid care partners to treat and manage the PWP/PRD's medical condition. Whether you are a PWP/PRD or a care partner, please describe the costs on behalf of the PWP/PRD's entire household and unpaid care partner to the best of your knowledge. Please provide all money amounts in *US dollars, regardless of whether you live in the US or not*.

Text entry, required

16. In the past 12 months, approximately how much was spent by the PWP/PRD's household and care partners (not by the insurance company) on **prescriptions**? Please provide your best estimate in the table below, rounded to the nearest dollar amount. Please enter 0 in the text box if money was not spent.

	All Prescriptions (\$ USD)	Prescriptions for Treating PD/PRD (\$ USD)
Paid by the PWP/PRD or the family	_____	_____

Text entry, required

17. In the past 12 months, approximately how much was spent by the PWP/PRD's household and care partners (not by insurance company) on **products** (e.g., Over the Counter (OTC) medications, supplements), **supplies** (e.g., special/adapted clothing, equipment for feeding, other supplies), **durable medical equipment**, **activities** (e.g., gym, exercise classes, online classes) intended to manage their condition, and **counseling** for PWP/PRD and care partners? Please provide your best estimate in the table below, rounded to the nearest dollar amount. Please enter 0 in the text box if money was not spent.

	Products (OTC and supplements) (\$ USD)	Supplies (adaptive clothing, feeding equipment) (\$ USD)	Durable medical equipment (\$ USD)	Activities (gym, exercise classes, online classes, home exercise equipment) (\$ USD)	Counseling (patient education, psychotherapy, nutrition counseling, dietician) for PWP/PRD and care partners (\$ USD)
Paid by the PWP/PRD or the family	_____	_____	_____	_____	_____

Text entry, required

18. In the past 12 months, approximately **how many months** did you (if you have PD/PRD), or the PWP/PRD you care for live in/or spend time at each of the following places? Note: Please enter 0 in the text box if no time was spent in the place listed. Please round up partial months (e.g., if time spent was more than three but less than four months, please enter 4).

	Length of Time (Months)
Private residence (e.g., home, townhouse, condo) (alone)	_____
Private residence (e.g., home, townhouse, condo) (with someone)	_____
Adult day care facility	_____
Adult outpatient rehab facility	_____
Active adult or senior living community	_____
Hospice facility	_____
Nursing home (long-term residential care)	_____
Skilled Nursing Facilities (Short-term transitional care after an illness, injury, or surgery)	_____
Other “long-term” care facilities (e.g., assisted living, memory care, medical foster care, other residential care)	_____

Text entry, required

19. In the past 12 months, approximately how much was spent by the PWP/PRD’s household and care partners for the stay in the facility/institution? Please provide your best estimate in the table below, rounded to the nearest dollar amount. Please enter 0 in the text box if no money was spent on the associated facility/institution.

	Amount Spent (\$ USD)
Adult day care facility <i>(show if the response to “Adult day care facility” in Q18 was greater than 0)</i>	_____
Adult outpatient rehab facility <i>(show if the response to “Adult outpatient rehab facility” in Q18 was greater than 0)</i>	_____
Active adult or senior living community <i>(show if the response to “Active adult or senior living community” in Q18 was greater than 0)</i>	_____
Hospice facility <i>(show if the response to “Hospice facility” in Q18 was greater than 0)</i>	_____
Nursing home (long-term residential care) <i>(show if the response to “Nursing home” in Q18 was greater than 0)</i>	_____
Skilled Nursing Facilities (Short-term transitional care after an illness, injury, or surgery) <i>(show if the response to “Nursing home” in Q18 was greater than 0)</i>	_____

	Amount Spent (\$ USD)
Other “long-term” care facilities (e.g., assisted living, memory care, medical foster care, other residential care) <i>(show if the response to “Other ‘long-term’ care facilities” in Q18 was greater than 0)</i>	_____

Matrix table, single answer, required

20. In the past 12 months, did you (if you have PD/PRD), or the PWP/PRD you care for receive any of the following types of **disability income**? *Check and answer all that apply.*

	Yes	No	Don’t Know
Supplemental Security Income (SSI)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social Security Disability Insurance (SSDI)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other Types of Disability Income	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Matrix table (text entry), required

a. Provide the total amount received from disability income in the past 12 months, before tax, and rounded to the nearest dollar amount.

	Total Amount In the Past 12 Months (\$ USD Before Tax)
Supplemental Security Income (SSI) <i>(only show if response to Q20 for SSI was “Yes”)</i>	_____
Social Security Disability Insurance (SSDI) <i>(only show if response to Q20 for SSDI was “Yes”)</i>	_____
Other Types of Disability Income <i>(only show if response to Q20 for Other Types of Disability Income was “Yes”)</i>	_____

Display logic: If “Yes” count is greater than 0 for “In the past 12 months, did you (if you have PD/PRD), or the PWP/PRD you care for receive any of the following types of **disability income**?”

Text entry, required

21. In the past 12 months, how much has the PWP/PRD’s household and care partners spent on each of the expenses that you **would not have spent otherwise, due to care needs for the PWP/PRD**? Please provide your best estimate in the table below, rounded to the nearest dollar amount. Please enter 0 in the text box if there was no money spent.

		Amount Spent (\$ USD)
a.	Expenses on home modifications (e.g., building a ramp in place of steps to enter/exit home)	_____
b.	One-time costs incurred for moving or purchasing a residence necessary to meet care needs (e.g., moving company fees, closing costs to purchase an accessible home)	_____
c.	Expenses related to purchasing a special vehicle or purchasing/installing special equipment on a car or other motor vehicle	_____
d.	Expenses to hire someone (e.g. a professional, relative, or friend) to provide daily care	_____
e.	Expenses to hire someone to do household chores/provide services other than patient care (e.g., shopping, meal preparation, delivery, house cleaning, gardening, taking care of other dependents, etc.)	_____
f.	<p>Increased transportation costs (e.g. driving, taking taxis or rideshares to and from clinics, rehab facilities, visiting PWP who live in nursing home, etc.)</p> <p><i>For example, drives an extra 20 miles per month (240 miles per year) for appointments. This is equivalent to approximately one tank of gas at about \$30 a tank; the resulting amount is \$30.</i></p>	_____
g.	Expenses related to financial and legal planning	_____
h.	<p>Expenses related to care partner's respite care, defined as a short-term break given to the caregiver to rest, travel, or spend time with other family and friends for a few hours to several weeks at a time. Respite care can take place inside or outside the home, including in a health care facility, or at an adult day care center.</p>	_____



Multiple choice, single answer, required

22. In the past 12 months, on average, about how many hours of **daily care** (paid or unpaid, including providing supervision, coordinating care, and/or accompanying to health care visits) did you (if you have PD/PRD), or the PWP/PRD you care for require *on a typical day*?
- a) None
 - b) Between 0-4 hours
 - c) Between 4-8 hours
 - d) Between 8-12 hours
 - e) Between 12-16 hours
 - f) More than 16 hours
 - g) Not applicable

Text entry, required, only appears if PWP/PRD received care from an unpaid primary care partner or an unpaid Non-Primary Care Partner in Q11

Validation: Allow only number format, Number between 0 – 24

23. **(PWP/PRD ONLY)** To the best of your knowledge, how many hours do all your unpaid care partner(s) spend caring for you in a typical day, on average? Please round up partial hours (e.g., if time spent was more than three but less than four hours, please enter 4).

	Hours spent providing care to you in a typical day
All Unpaid Care Partner(s)	_____

Display logic: If (a. A person with Parkinson's disease or Parkinson's related disorder) is selected for "Which of the following **best describes you**" AND if "Yes" is selected for "In the past 12 months, have you, or the PWP/PRD you care for, received care from at least one **unpaid** care partner?"

Text entry, required, only appears if PWP/PRD received care from an unpaid primary care partner or an unpaid Non-Primary Care Partner in Q11

24. **(CARE PARTNER ONLY)** To the best of your knowledge, how many hours do you and all the other unpaid care partner(s) spend caring for the PWP/PRD in a typical day, on average? Please round up partial hours (e.g., if time spent was more than three but less than four hours, please enter 4).

	Hours spent providing care to the PWP/PRD in a typical day
You	_____
All Other Unpaid Care Partner(s)	_____

Display logic: If (b.) or (c.) is selected for "Which of the following **best describes you**" AND if "Yes" is selected for "In the past 12 months, have you, or the PWP/PRD you care for, received care from at least one **unpaid** care partner?"

Date entry, required



25. **(CARE PARTNERS ONLY)** When did you start providing care for the PWP/PRD? Please enter your best guess if you are not sure.

_____ (mm/dd/yyyy dropdown from calendar)

Display logic: If (b.) or (c.) is selected for “Which of the following **best describes you**”

Multiple choice, single answer, required

26. What is your (the person answering this survey) current job status?

a. Employed or self-employed full-time	<input type="checkbox"/>
b. Employed or self-employed part-time	<input type="checkbox"/>
c. Not employed or self-employed, but seeking work	<input type="checkbox"/>
d. Not employed or self-employed, but in school	<input type="checkbox"/>
e. Not employed or self-employed, not seeking work and not in school	<input type="checkbox"/>
f. Retired	<input type="checkbox"/>
g. Not applicable	<input type="checkbox"/>



Text entry, required only appears if PWP/PRD, primary care partner, or Non-Primary Care Partner answered “Employed full-time” or “Employed part-time” to Q25

Validation: In number format only, don’t allow numbers greater than 168

27. How many hours do you (the person answering this survey) usually work in a typical **week**?

Please round up partial hours (e.g., if time worked was more than thirteen but less than fourteen hours, please enter 14).

Hours worked in a typical week	_____
--------------------------------	-------

Display logic: If (a.) or (b.) is selected for “What is your current job status?”

Text entry, required

28. During the past 12 months, how many **months** were you (the person answering this survey) employed (full or part time)? Include any time on paid vacation, paid sick leave, jury duty, or military service. Please round up partial months (e.g., if time employed was more than three but less than four months, please enter 4).

Months employed in the past 12 months	_____
---------------------------------------	-------

Display logic: If (a.) or (b.) is selected for “What is your current job status?”

Dropdown, required only appears if PWP/PRD, primary care partner, or Non-Primary Care Partner answered “Not employed, but seeking work,” “Not employed, not seeking work and not in school” or “Retired” to Q25

29. In which **year** did you (the person answering this survey) **retire/last worked**?

Year retired or last worked	_____
-----------------------------	-------

Display logic: If (c.), (e.), or (f.) is selected for “What is your current job status?”

Multiple choice, single answer, required, only appears if PWP/PRD, primary care partner, or Non-Primary Care Partner answered “Not employed, but seeking work,” “Not employed, not seeking work and not in school” or “Retired” to Q25

30. Did your PD/PRD or care partner responsibilities play a major role in your decision to stop working?

	Yes, it played a role	No, it did not play a role	Don’t know
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Display logic: If (c.), (e.), or (f.) is selected for “What is your current job status?”



Text entry, required; however, if the response to the PWP/PRD's months employed in Q27 was "0" this questions should be skipped.

Validation: *Number between 0 – 31*

31. In a typical month during the past 12 months, about how many days did you miss work at a job or business or feel less productive while at work, because of PD/PRD or care partner responsibilities? Please round up partial days (e.g., if time missed was more than three but less than four days, please enter 4).

	Days
Days missed from work (include whole days missed as well as days when individual was late or left work early) (Days)	_____
Days felt less productive at work (Days)	_____

Display logic: If "Months employed in the past 12 months" is greater than 0 for "During the past 12 months, **how many months were you employed** (full or part time)?"

Multiple choice, multiple answer, required

32. Have any of the following **ever** applied to you for reasons related to your PD/PRD or care partner responsibilities? *Please select all that apply.*

Lost educational opportunity	<input type="checkbox"/>
Stopped working at your job (e.g., early retirement)	<input type="checkbox"/>
Worked fewer hours at your job	<input type="checkbox"/>
Changed work hours to a different time of the day	<input type="checkbox"/>
Changed to flexible hours or telecommuting	<input type="checkbox"/>
Lost opportunities for a better job or promotion	<input type="checkbox"/>
Changed occupation or employer	<input type="checkbox"/>
Been unable to take a job	<input type="checkbox"/>
Postponed, skipped or canceled routine health care (e.g., annual physical exam)	<input type="checkbox"/>

None of these

☐

Text entry, required (can be 0)

33. Considering the various ways your job has been impacted from the items in the previous question and any other applicable factors, provide the best estimate for your **total loss in annual earnings** in the *past 12 months, rounded to the nearest dollar amount*.

Approximate Loss in Annual Earnings (\$ USD)	_____
---	-------

Matrix table (text entry), required

Validation: *Number format, don't allow numbers greater than 168*

34. Please tell us the approximate number of hours in a typical week you were able to participate in the following activities, **before** your PD/PRD or care partner responsibilities started having an impact. Then, tell us how many hours in a typical week you spend participating in the following activities **now**. Please round up partial hours (e.g., if time spent was more than three but less than four hours, please enter 4).

Typical hours per week	Before PD/PRD started having an impact	Now
Performing voluntary or charity work	_____	_____
Visiting with friends or relatives	_____	_____
Providing help to family, friends, or neighbors unrelated to personal care	_____	_____
Attending an educational or training course	_____	_____
Attending a sporting event or social or other type of club	_____	_____
Participation in a religious organization (e.g., church, synagogue, mosque)	_____	_____
Participating in a political or community-related organization	_____	_____
Eating a meal at a restaurant or outside of home	_____	_____
Independently doing household chores	_____	_____

Multiple choice, single answer, required

35. **(CARE PARTNER ONLY)** During the past 12 months, how much were you **affected physically** by providing care to the PWP/PRD?

	Not at all	A little bit	A moderate amount	Quite a bit	An extreme amount
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Display logic: If (b.) or (c.) is selected for “Which of the following **best describes you?**”

Multiple choice, single answer, required

36. **(CARE PARTNER ONLY)** During the past 12 months, how much were you **affected emotionally** by providing care to the PWP/PRD?

	Not at all	A little bit	A moderate amount	Quite a bit	An extreme amount
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Display logic: If (b.) or (c.) is selected for “Which of the following **best describes you?**”

Multiple choice, single answer, required

37. **(CARE PARTNER ONLY)** During the past 12 months, how much were you **affected financially** by providing care to the PWP/PRD?

	Not at all	A little bit	A moderate amount	Quite a bit	An extreme amount
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Display logic: If (b.) or (c.) is selected for “Which of the following **best describes you?**”



End of Survey Thank You

Thank you for your participation in this survey. The information you provided is very important to help us better understand the disease and its impact on individuals and families. **Please click on the next arrow below (>>) to submit your responses and be redirected to the Fox Insight website.**

End of Survey Thank You 2

Thank you for participating in Fox Insight. This survey is currently only collecting responses from People with PD/PRD or unpaid Care Partners who have provided care to someone with PD/PRD within the past 12 months. **Please click on the next arrow below (>>) to submit your responses and be redirected to the Fox Insight website.**