

The Financial and Social Impact of Parkinson's Disease Survey

Start of Block: Introduction

Q1 The Financial and Social Impact of Parkinson's Disease Survey Funded by The Michael J. Fox Foundation and the Parkinson's Foundation

Survey Overview Parkinson's disease can put financial and social costs on patients and their families. To better understand these costs, The Michael J. Fox Foundation and the Parkinson's Foundation 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. The results will be used in discussions with lawmakers and others to advocate for policies to improve the lives of people with Parkinson's and their families. Please note that participation in this survey is voluntary.

You should take this survey if: You or someone in your family has Parkinson's disease, You are familiar with your family's finances, and You know your family's Parkinson's health care needs.

Please fill out only one survey per family. You can ask family members to help answer questions. 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 is formatted to best fit a computer screen so please complete the survey from a computer if possible. Added this suggestion from Ted. The survey should take no more than forty (40) minutes to complete. You can take the survey any time before October 10th, 2018. Please try your best to answer all the questions. If you are not sure about a question, your best estimate is fine. All of the information you provide will be de-identified, meaning that your name will not be connected to the other information you share. As such, there are minimal, if any, foreseeable risks or discomfort to the survey participant. Your answers will be included along with answers from other participants and will be shared with qualified researchers. By participating in this survey, you are giving your consent for your de-identified information to be used for research.

If you have questions or need help completing the survey, email the Fox Insight team at info@foxinsight.org.

Thank you for taking part in this important survey!

End of Block: Introduction

Start of Block: Section A: Health Status

Q2 Section A: Health Status

This section asks about the health of the person with Parkinson's (PWP), including their diagnosis history and current symptoms. **Please note: If the PWP in your family has passed away, please answer the questions as best you can based on your knowledge of his/her experience before passing away.**

Q3 Which of the following **best describes you** (the person who is responding to this survey)?

- ☐ A person with PD (1)
- ☐ A care partner for someone who has PD (2)
- ☐ A family member to someone who has PD, but not a care partner (3)
- ☐ A close friend of someone who has PD, but not a care partner (4)
- ☐ Do not have PD and do not know anyone with PD (5)

Skip To: End of Survey If Q3 = 5

Display This Question:

If Q3 = 2

Or Q3 = 3

Or Q3 = 4

Or Q3 = 5

Q4 If the PWP has passed away, please tell us when they passed away. **Note:** Please select from the drop down list.

- ☐ 2018 (1)
- ☐ 2017 (2)
- ☐ 2016 (3)
- ☐ 2015 (4)
- ☐ 2014 (5)
- ☐ 2013 (6)
- ☐ 2012 (7)
- ☐ 2011 (8)
- ☐ 2010 (9)
- ☐ 2009 (10)
- ☐ 2008 (11)
- ☐ 2007 (12)
- ☐ 2006 (13)
- ☐ 2005 (14)
- ☐ 2004 (15)
- ☐ 2003 (16)
- ☐ 2002 (17)
- ☐ 2001 (18)
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- ☐ 1999 (20)

- ☐ 1998 (21)
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- ☐ 1990 (29)
- ☐ 1989 (30)
- ☐ 1988 (31)
- ☐ 1987 (32)
- ☐ 1986 (33)
- ☐ 1985 (34)
- ☐ 1984 (35)
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- ☐ 1981 (38)
- ☐ 1980 (39)
- ☐ 1979 (40)
- ☐ 1978 (41)

- ☐ 1977 (42)
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 - ☐ 1929 (90)
 - ☐ 1928 (91)
 - ☐ 1927 (92)
 - ☐ 1926 (93)
 - ☐ 1925 (94)
 - ☐ 1924 (95)
 - ☐ 1923 (96)
 - ☐ 1922 (97)
 - ☐ 1921 (98)
 - ☐ 1920 (99)
 - ☐ 1919 (100)
 - ☐ 1918 (101)
-

Q6 In which year was the PWP **first diagnosed** with the disease? **Note:** Please select from the drop down list.

- ☐ 2018 (1) _____
- ☐ 2017 (2)
- ☐ 2016 (3)
- ☐ 2015 (4)
- ☐ 2014 (5)
- ☐ 2013 (6)
- ☐ 2012 (7)
- ☐ 2011 (8)
- ☐ 2010 (9)
- ☐ 2009 (10)
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- ☐ 1979 (40)
- ☐ 1978 (41)

- ☐ 1977 (42)
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- ☐ 1969 (50)
- ☐ 1968 (51)
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- ☐ 1928 (91)
- ☐ 1927 (92)
- ☐ 1926 (93)
- ☐ 1925 (94)
- ☐ 1924 (95)
- ☐ 1923 (96)
- ☐ 1922 (97)
- ☐ 1921 (98)
- ☐ 1920 (99)
- ☐ 1919 (100)
- ☐ 1918 (101)

Q7 If the PWP 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 from normal activities. **Moderate:** The symptom/condition is usually

present, some help/device is needed, and it occasionally keeps the PWP from normal activities.

Severe: PWP needs assistance to cope with problem. However, even with assistance, the PWP finds problems participating in normal activities.

	Did not experience the symptom (1)	Mild (2)	Moderate (3)	Severe (4)
Slow movement (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tremors (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Poor balance and coordination (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Trouble speaking (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Trouble writing (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Urinary issues such as urinary urgency or loss of bladder control (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Constipation or irritable bowel syndrome (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sleep issues (such as trouble falling asleep, staying asleep, abnormal dreams, etc.) (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fatigue and loss of energy (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulty with concentrating (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulty with memorizing or recalling information (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Difficulty with
understanding
requirements to
complete
complex tasks
(12)

☐☐☐☐

Difficulty with
swallowing (13)

☐☐☐☐

Vision problems
(14)

☐☐☐☐

Pain (15)

☐☐☐☐

Q8 Has the PWP ever been diagnosed with any of the below **conditions**? Check *all that apply*.

- ☐ Alzheimer's disease (1)
 - ☐ Dementia (2)
 - ☐ Bipolar disorder (3)
 - ☐ Schizophrenia (4)
 - ☐ Hallucinations or delusions (5)
 - ☐ Depression (6)
 - ☐ Anxiety (7)
 - ☐ Apathy (e.g., a lack of interest or enthusiasm) (8)
 - ☐ Other kind of psychotic disorders (9)
 - ☐ Other personality or behavioral disorders (10)
 - ☐ None of the above (11)
-

Q9 In the past 12 months, did the PWP use any mobility **assistance devices** (e.g., walker, wheelchair, etc.) for reasons related to PD?

- ☐ Yes (1)
 - ☐ No (2)
 - ☐ Don't know (3)
-

Display This Question:

If Q9 = 1



Q10 If yes, approximately how many weeks (in the past 12 months) did the PWP use any of the following devices? Responses can include decimals to account for a partial week. Note: Please enter 0 in the text box if the device was not used.

	Weeks relying on a walking device in the past 12 months (1)
Walkers (1)	
Wheelchairs (2)	
Canes (3)	
Scooters (4)	

Q11 In the past 12 months, has the PWP experienced **OFF periods** (periods during which the PWP's Parkinson's **medications seemed to "wear off"** causing symptoms of PD to partially or fully return)?

- ☐ Yes (1)
- ☐ No (2)
- ☐ Don't know (3)

Display This Question:

If Q11 = 1

Q12 If yes, approximately how many of the PWP's waking hours in a typical day are **spent in an OFF state**?

- ☐ Less than 1 hour (1)
 - ☐ Between 1-2 hours (2)
 - ☐ Between 2-3 hours (3)
 - ☐ Between 3-4 hours (4)
 - ☐ Greater than 4 hours (5)
-

Q13 In the past 12 months, has the PWP experienced **dyskinesia (uncontrolled, involuntary movement)** from long-term use of PD medications such as Levodopa?

- ☐ Yes (1)
 - ☐ No (2)
 - ☐ Don't know (3)
-

Display This Question:

If Q13 = 1

Q14 If yes, approximately how many of the PWP's waking hours in a typical day are **spent in a dyskinesia state**?

- ☐ Less than 1 hour (1)
 - ☐ Between 1-2 hours (2)
 - ☐ Between 2-3 hours (3)
 - ☐ Between 3-4 hours (4)
 - ☐ Greater than 4 hours (5)
-

Q15 Has the PWP ever received any type of **device-assisted therapy** (such as those listed below) for treating the symptoms of PD? Check *all that apply*.

- ☐ Deep Brain Stimulation (surgical procedure used to address tremor and other PD symptoms) (1)
- ☐ Duopa or Levodopa-Carbidopa Intestinal Gels (a non-oral Levodopa medication that is delivered continuously into the intestine) (2)
- ☐ Apomorphine Infusion (a pen or pump-like, injectable device used to deliver medication to address when the medication is "wearing off," or when Levodopa medication is no longer working) (3)
- ☐ Neupro Patch (4)
- ☐ Don't know (5)
- ☐ None of the above (6)

End of Block: Section A: Health Status

Start of Block: Section B: Family Characteristics and Health Insurance Coverage

Q16 Section B: Family Characteristics and Health Insurance Coverage

This section asks questions about the **demographic information** of the person with Parkinson's (PWP) and the unpaid care partners. 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 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 as the **primary care partner**. Please refer to the individual who provides unpaid care to the PWP, but less frequently than the primary care partner, as the **secondary care partner**.

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

Q17 Where does the PWP currently live? *Please respond based on where the PWP physically resides.*

- ☐ Urbanized area (comprised of at least 50,000 residents) (1)
 - ☐ Urban clusters/suburban areas (comprised of at least 2,500 residents, but fewer than 50,000 residents) (2)
 - ☐ Rural area (comprised of open country and settlements with fewer than 2,500 residents) (3)
 - ☐ Do not know (4)
-

Q18 What type of **insurance** does the PWP currently have? *Check the appropriate box for each type of health insurance.*

	Yes (1)	No (2)	Don't Know (3)
Commercial Insurance through Employer (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Individual Commercial Insurance (Private) (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medicaid/SCHIP (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medicare Part A (Hospital Insurance) (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medicare Part B (Medical Insurance) (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medicare Part C (Medicare Advantage) (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medicare Part D (Prescription Drug Coverage) (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Military/CHAMPUS/TRICARE (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Uninsured (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Display This Question:

If Q18 = 9 [1]



Q19 If the PWP **does not currently have any health insurance coverage**, approximately how many months has he/she been without coverage?



Q20 In the past 12 months, approximately how much was spent by the PWP or the family (not by the insurance company) on medications? Please provide your best estimate in the table below. **Note:** Please enter 0 in the text box if money was not spent.

	All Medications (\$) (1)	Medications for Treating PD (\$) (2)
Paid by the PWP or the Family (1)		

Q21 How many people (exclude paid professional caregivers) are in the PWP's household, **not** including the PWP?

	None (1)	One (2)	Two (3)	Three (4)	Four or More (5)
Adults (age 18 and over) (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Children (under age 18) (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



Q22 In the past 12 months, has the PWP received care from at least one **unpaid** care partner?

	Yes (1)	No (2)	Not Applicable (3)
Primary Care Partner (the individual who spent the most time providing unpaid care to the PWP) (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Secondary Care Partner (the individual who provides unpaid care to the PWP, but less frequently than the primary care partner) (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*

Q24 What is the current **age** of the PWP and each of the unpaid care partner(s)?

	PWP (1)	Q22 = 1 [1] Primary Care Partner (2)	Q22 = 2 [1] Secondary Care Partner (3)
Age (1)			

Q25 What is the **sex** of the PWP and each of the unpaid care partner(s)?

	Male (1)	Female (2)	Prefer not to answer (3)
PWP (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q22 = 1 [1]			
Primary Care Partner (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q22 = 2 [1]			
Secondary Care Partner (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q26 What is the **race** of the PWP and each of the unpaid care partner(s)?

	American Indian or Alaska Native (1)	Asian (2)	Black or African American (3)	Multi-racial (4)	Native Hawaiian or Other Pacific Islander (5)	White or Caucasian (6)	Other (7)	Prefer not to answer (8)
PWP (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q22 = 1 [1]								
Primary Care Partner (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q22 = 2 [1]								
Secondary Care Partner (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q27 What is the **ethnicity** of the PWP and each of the unpaid care partner(s)?

	Hispanic (1)	Non-Hispanic (2)	Prefer not to answer (3)
PWP (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q22 = 1 [1]			
Primary Care Partner (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q22 = 2 [1]			
Secondary Care Partner (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q29 What is the **highest level of education** attained by the PWP and each of the unpaid care partner(s)?

	Less than a high school degree (1)	High school degree (GED or equivalent) (2)	Some College (1-4 years, no degree) (3)	Associate's Degree (AS, AAS, etc.) (4)	Bachelor's Degree (BA, BS, etc.) (5)	Master's Degree (MA, MS, etc.) (6)	PhD or Professional School Degree (MD, JD, etc.) (7)	Pre not ans (8)
PWP (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Q22 = 1 [1]								
Primary Care Partner (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Q22 = 2 [1]								
Secondary Care Partner (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	

Q30 What is the **marital status** of the PWP and each of the unpaid care partner(s)?

	Married / Living with partner (1)	Widowed (2)	Divorced / Separated (3)	Never Married (4)	Prefer not to answer (5)	Don't know (6)
PWP (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q22 = 1 [1]						
Primary Care Partner (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q22 = 2 [1]						
Secondary Care Partner (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q31 What were the **total earnings** of the PWP, the entire household of the PWP and each of the unpaid care partner(s) **in the most recent tax year**? Please select the appropriate response category for each party in the table below.

Note: This includes the amount received through wages, salary, commissions, overtime pay, or tips from all jobs before taxes or other deductions, and exclude 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 the PWP, and excludes co-residents who are financially independent and all paid care partners who are not family members.

	Less than \$25,000 (1)	\$25,000 to less than \$50,000 (2)	\$50,000 to less than \$75,000 (3)	\$75,000 to less than \$100,000 (4)	\$100,000 to less than \$125,000 (5)	\$125,000 to less than \$150,000 (6)	\$150,000 to less than \$175,000 (7)	\$175,000 to less than \$200,000 (8)	More than \$200,000 (9)
PWP (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q22 = 1 [1]									
Primary Care Partner (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q22 = 2 [1]									
Secondary Care Partner (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q21 = 1 [2] Or Q21 = 1 [3] Or Q21 = 1 [4] Or Q21 = 1 [5]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Household of the PWP (4)									

End of Block: Section B: Family Characteristics and Health Insurance Coverage

Start of Block: Section C: Financial Impact of Parkinson's Disease

Q32 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 (PWP), the care partners and their family. These financial impact 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 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 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 as the **primary care partner**. Please refer to the individual who provides unpaid care to the PWP, but less frequently than the primary care partner, as the **secondary care partner**. **As noted above, if the PWP in your family has passed away, please answer the questions as best you can based on his/her experience before passing away.**



Q33 In the past 12 months, approximately **how many months** did the PWP live in each of the following places? Note: Please enter 0 in the text box if no time was spent in the place listed.

	Length of Time (Months) (1)
Private home (alone) (1)	
Private home (with someone) (2)	
Nursing home (3)	
Hospice Facility (4)	
Active adult or senior living community (5)	
Other "long-term" care facilities (6)	



Q34 If the PWP spent any time in the following facilities/institutions in the past 12 months, approximately how much was spent by the PWP or the family for the stay in the facility/institution? Note: Please enter 0 in the text box if no money was spent on the associated facility/institution.

	Amount Spent (\$) (1)
Adult day care facility (1)	
Adult outpatient rehab facility (2)	
<p><i>If In the past 12 months, approximately how many months did the PWP live in each of the following pl... Hospice Facility - Length of Time (Months) Is Greater Than 0</i></p> <p>Hospice care in a facility (3)</p>	
<p><i>If In the past 12 months, approximately how many months did the PWP live in each of the following pl... Nursing home - Length of Time (Months) Is Greater Than 0</i></p> <p>Nursing home (4)</p>	
Skilled Nursing Facilities (5)	
<p><i>If In the past 12 months, approximately how many months did the PWP live in each of the following pl... Other "long-term" care facilities - Length of Time (Months) Is Greater Than 0</i></p>	

Other “long-term” care facilities (6)

Q35 In the past 12 months, did the PWP receive any of the following types of **disability income**? If so, what was the amount received? *Check and answer all that apply.*

	Yes (1)	No (2)	Don't Know (3)
Supplemental Security Income (SSI) (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social Security Disability Insurance (SSDI) (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other Types of Disability Income (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Display This Question:

If Q35 = 1 [1]

Or Q35 = 2 [1]

Or Q35 = 3 [1]



Q40 If yes, provide the total amount received from disability income in the past 12 months.

	Total Amount In the Past 12 Months (\$ Before Tax) (1)
<div>Q35 = 1 [1]</div> Supplemental Security Income (SSI) (1)	
<div>Q35 = 2 [1]</div> Social Security Disability Insurance (SSDI) (2)	
<div>Q35 = 3 [1]</div> Other Types of Disability Income (3)	



Q36 In the past 12 months, how much has PWP or the family spent for each of the following reasons, as a result of caring for the PWP? Note: Please enter 0 in the text box if there was no money spent.

	Amount paid using sources such as family income, savings, gifts from relatives, loans, credit card debts, early retirement withdrawal, home equity loan, etc.) (\$) (1)
Expenses on home modifications (e.g., building a ramp in place of steps to enter/exit home) (1)	
Expenses related to purchasing a special vehicle or purchasing/installing special equipment on a car or other motor vehicle (2)	
Expenses related to hiring someone (e.g. a professional, relative, or friend) to provide daily care (3)	
Increased transportation costs (e.g. driving to and from clinics, rehab facilities, etc.) <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 per month (\$360 per year).</i> (4)	

Q37 In the past 12 months, on average, about how many hours of daily care (paid or unpaid, including providing supervision) did the PWP require on a typical day?

- ☐ None (1)
- ☐ Between 0-4 hours (2)
- ☐ Between 4-8 hours (3)
- ☐ Between 8-12 hours (4)
- ☐ Between 12-16 hours (5)
- ☐ Requires almost round-the-clock supervision (6)
- ☐ Not applicable (7)

Display This Question:

If Q22 = 1 [1]

Or Q22 = 2 [1]

Q38 Please describe the relationship of the unpaid care partner(s) to the PWP in the table below.

	Spouse/partner/significant other (1)	Parent (2)	Child (3)	Friend (4)	Other (5)
Q22 = 1 [1]					
Primary Care Partner (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q22 = 2 [1]					
Secondary Care Partner (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Display This Question:

If Q22 = 1 [1]

Or Q22 = 2 [1]



Q41 Approximately how many hours does the unpaid care partner(s) spend caring for the PWP in a typical week? Additionally, please report the combined hours spent by **all unpaid care partners** including the primary, secondary and all other unpaid care partners (if there were any).

	Hours spent providing unpaid care to the PWP in a typical week (1)
<div>Q22 = 1 [1]</div> <div>Primary Care Partner (1)</div>	
<div>Q22 = 2 [1]</div> <div>Secondary Care Partner (2)</div>	
<div>Q22 = 1 [1]</div> <div>And Q22 = 2 [1]</div> <div>All Other Care Partners Combined (3)</div>	

Display This Question:

If Q22 = 1 [1]

Or Q22 = 2 [1]



Q42 In which year did each of the unpaid care partners start providing care to the PWP? Note: Please enter in an yyyy format.

	Year first began to provide care and assistance to the PWP (1)
<div>Q22 = 1 [1]</div> <div>Primary Care Partner (1)</div>	
<div>Q22 = 2 [1]</div> <div>Secondary Care Partner (2)</div>	

Q43 What is the **current job status** of the PWP and each of the unpaid care partner(s)?

	Employed full-time (1)	Employed part-time (2)	Not employed, but seeking work (3)	Not employed, but in school (4)	Not employed, not seeking work and not in school (5)	Retired (6)	Not Applicable (7)
PWP (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q22 = 1 [1]							
Primary Care Partner (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q22 = 2 [1]							
Secondary Care Partner (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Display This Question:

If Q43 = 1 [1]

Or Q43 = 1 [2]

Or Q43 = 2 [1]

Or Q43 = 2 [2]

Or Q43 = 3 [1]

Or Q43 = 3 [2]



Q45 If currently employed, how many hours does each individual usually work in a typical week?

	<div> <div>Q43 = 1 [1]</div> <div>Or Q43 = 1 [2]</div> </div> <div>PWP (1)</div>	<div> <div>Q43 = 2 [1]</div> <div>Or Q43 = 2 [2]</div> </div> <div>Primary Care Partner (2)</div>	<div> <div>Q43 = 3 [1]</div> <div>Or Q43 = 3 [2]</div> </div> <div>Secondary Care Partner (3)</div>
Hours worked in a typical week (1)			



Q46 During the past 12 months, **how many months was each person employed** (full or part time)? Note: Include any time the person worked or was on paid vacation, paid sick leave, jury duty, or military service.

	<div>PWP (1)</div>	<div> <div>Q22 = 1 [1]</div> <div>Primary Care Partner (2)</div> </div>	<div> <div>Q22 = 2 [1]</div> <div>Secondary Care Partner (3)</div> </div>
Months employed in the past 12 months (1)			

Display This Question:

If Q43 = 1 [3]

Or Q43 = 1 [5]

Or Q43 = 1 [6]

Or Q43 = 2 [3]

Or Q43 = 2 [5]

Or Q43 = 2 [6]

Or Q43 = 3 [3]

Or Q43 = 3 [5]

Or Q43 = 3 [6]



Q47 If the PWP or unpaid care partner(s) is no longer working or currently retired, **in which year did he or she retire/stop working?** Note: Please enter in an yyyy format.

	Year retired or stopped working (1)
<div><div>Q43 = 1 [3] Or Q43 = 1 [5] Or Q43 = 1 [6]</div><div>PWP (1)</div></div>	
<div><div>Q43 = 2 [3] Or Q43 = 2 [5] Or Q43 = 2 [6]</div><div>Primary Care Partner (2)</div></div>	
<div><div>Q43 = 3 [3] Or Q43 = 3 [5] Or Q43 = 3 [6]</div><div>Secondary Care Partner (3)</div></div>	

Display This Question:

If Q43 = 1 [3]

Or Q43 = 1 [5]

Or Q43 = 1 [6]

Or Q43 = 2 [3]

Or Q43 = 2 [5]

Or Q43 = 2 [6]

Or Q43 = 3 [3]

Or Q43 = 3 [5]

Or Q43 = 3 [6]

Q56 If the PWP or unpaid care partner(s) is no longer working or currently retired, did PD play a major role in his/her decision to stop working?

	Yes, PD played a role (1)	No, PD did not play a role (2)	Don't know (3)
<div>Q43 = 1 [5]</div> <div>Or Q43 = 1 [6]</div> <div>Or Q43 = 1 [3]</div> <div>PWP (1)</div>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<div>Q43 = 2 [3]</div> <div>Or Q43 = 2 [5]</div> <div>Or Q43 = 2 [6]</div> <div>Primary Care Partner (2)</div>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<div>Q43 = 3 [3]</div> <div>Or Q43 = 3 [5]</div> <div>Or Q43 = 3 [6]</div> <div>Secondary Care Partner (3)</div>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Display This Question:

If During the past 12 months, how many months was each person employed (full or part time)?
Note: In... Months employed in the past 12 months - **PWP** Is Greater Than 0



Q48 In an average working month during the past 12 months, about how many days did the PWP **miss work at a job or business or feel less productive while at work, because of PD?** Note: Response can include decimals to account for partial days missed.

	PWP (1)
Days missed from work (include whole days missed as well as days when individual was late or left work early) (Days) (1)	
Days felt less productive at work (Days) (2)	

Display This Question:

*If During the past 12 months, how many months was each person employed (full or part time)?
Note: In... Months employed in the past 12 months - Primary Care Partner Is Greater Than 0*

*Or During the past 12 months, how many months was each person employed (full or part time)?
Note: In... Months employed in the past 12 months - Secondary Care Partner Is Greater Than 0*



Q50 In an average working month during the past 12 months, about how many days did the unpaid care partner(s) **miss work at a job or business or feel less productive while at work, due to responsibilities caring for the PWP?** Note: Response can include decimals to account for partial days missed.

	<div> <p><i>If During the past 12 months, how many months was each person employed (full or part time)? Note: In... Months employed in the past 12 months -</i></p> <p><i>Primary Care Partner Is Greater Than</i></p> <p><i>0</i></p> </div> <p>Primary Care Partner (1)</p>	<div> <p><i>If During the past 12 months, how many months was each person employed (full or part time)? Note: In... Months employed in the past 12 months -</i></p> <p><i>Secondary Care Partner Is Greater Than</i></p> <p><i>0</i></p> </div> <p>Secondary Care Partner (2)</p>
Days missed from work (include whole days missed as well as days when individual was late or left work early) (Days) (1)		
Days felt less productive at work (Days) (2)		

Q51 Please select whether any of the below has **ever** applied to the PWP and their care partner(s) for reasons related to the individual's PD. *Check all that apply for each individual.*

	Lost opportunities for further education (1)	Stopped working at their job (e.g., early retirement), causing lost earnings, benefits, and pension (2)	Worked at job fewer hours (3)	Changed hours to a different time of the day (4)	Changed to flexible hours or telecommuting (5)	Lost opportunities for a better job or promotion (including missed opportunities for more comprehensive benefits) (6)	Other (7)
PWP (1)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
<div>Q22 = 1 [1]</div> Primary Care Partner (2)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
<div>Q22 = 2 [1]</div> Secondary Care Partner (3)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	



Q52 Considering the various ways each individual's job has been impacted from the items in the previous question and any other applicable factors, provide the best estimate for their total loss in annual earnings in the past 12 months.

	PWP (1)	Q22 = 1 [1] Primary Care Partner (2)	Q22 = 2 [1] Secondary Care Partner (3)
Approximate Loss in Annual Earnings (\$) (1)			



Q58 Please tell us the approximate number of hours in a typical week each person is able to participate in the following activities, **BEFORE** PD started having a significant impact.

	PWP (1)	Q22 = 1 [1] Primary Care Partner (2)	Q22 = 2 [1] SecondaryCare Partner (3)
Performing voluntary or charity work (1)			
Visiting with friends or relatives (2)			
Providing help to family, friends, or neighbors unrelated to personal care (3)			
Attending an educational or training course (4)			
Attending a sporting event or social or other type of club (5)			
Participating in a religious organization (e.g., church, synagogue, mosque) (6)			

Participating in a political or community-related organization (7)



Q60 Please tell us the approximate number of hours in a typical week each person is able to participate in the following activities, **AFTER** PD started having a significant impact.

	PWP (1)	Q22 = 1 [1] Primary Care Partner (2)	Q22 = 2 [1] SecondaryCare Partner (3)
Performing voluntary or charity work (1)			
Visiting with friends or relatives (2)			
Providing help to family, friends, or neighbors unrelated to personal care (3)			
Attending an educational or training course (4)			
Attending a sporting event or social or other type of club (5)			
Participating in a religious organization (e.g., church, synagogue, mosque) (6)			

Participating in a political or community-related organization (7)

Display This Question:

If Q22 = 1 [1]

Or Q22 = 2 [1]

Q54 During the past 12 months, how much **was the unpaid care partner(s) affected, either physically or emotionally**, by providing care to the PWP?

	None at all (1)	A little bit (2)	A moderate amount (3)	Quite a bit (4)	An extreme amount (5)
Q22 = 1 [1]					
Primary Care Partner (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q22 = 2 [1]					
Secondary Care Partner (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: Section C: Financial Impact of Parkinson’s Disease