

# Impact and communication about OFF periods

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Start of Block: Intro Text Block

## Q1 Impact and communication about OFF periods

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Q2 This survey seeks to understand how patients and care partners understand and communicate about OFF periods, and how OFF periods impact on patients and care partners. The survey should take about 25 minutes to complete.

End of Block: Intro Text Block

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Start of Block: PwP or CP

Q3 Do you have Parkinson's disease or are you the primary care partner for a person with Parkinson's disease?

- ☐ Yes, I have Parkinson's disease (1)
- ☐ Yes, I am the primary care partner for a person with Parkinson's disease (2)
- ☐ No (3)

*Skip To: End of Survey If Q3 = 3*

End of Block: PwP or CP

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Start of Block: PwP 1

Q50 When a person with Parkinson's disease benefits from medication, over time they can begin to experience periods where the medications don't work or don't work as well. In those periods those symptoms that are typically improved by the medication temporarily worsen. These periods are called **OFF periods**.

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Q51 Do you experience OFF periods, as just defined?

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

*Skip To: End of Survey If Q51 = 2*

*Skip To: End of Survey If Q51 = 3*

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Q52 Are you familiar with the term “OFF” or “OFF periods” related to Parkinson’s disease, as just presented and defined below?

*When a person with Parkinson’s disease benefits from medication, over time they can begin to experience periods where the medications don’t work or don’t work as well. In those periods those symptoms that are typically improved by the medication temporarily worsen. These periods are called **OFF periods**.*

- ☐ Yes (1)
- ☐ No (2)
- 

Page Break

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### Q53 PERSONAL EXPERIENCE OF OFF PERIODS

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Q54 How many years ago did you begin to experience OFF periods?

- ☐ Less than 1 year (1)
  - ☐ 1 to 5 years (2)
  - ☐ 6 to 10 years (3)
  - ☐ Greater than 10 years (4)
  - ☐ I don't know (5)
- 

Q55 Over the last week, on average, how many OFF periods do you experience in a typical waking day?

- ☐ No periods, zero (1)
  - ☐ 1 period per day (2)
  - ☐ 2 periods per day (3)
  - ☐ 3 periods per day (4)
  - ☐ Greater than 4 periods per day (5)
  - ☐ I don't know (6)
-

Q56 Over the last week, on average, what is the typical duration of each OFF period?

- ☐ Less than 15 minutes (1)
  - ☐ Between 15 and 30 minutes (2)
  - ☐ Between 30 and 45 minutes (3)
  - ☐ Between 45 minutes and 1 hour (4)
  - ☐ Greater than 2 hours (5)
  - ☐ I don't know (6)
- 

Q57 What proportion of your OFF periods come at unpredictable (i.e. unexpected) times?

- ☐ 0% (1)
  - ☐ Less than 25% (2)
  - ☐ 25-50% (3)
  - ☐ Greater than 50% (4)
  - ☐ I don't know (5)
- 

*Display This Question:*

*If Q57 = 2*

*Or Q57 = 3*

*Or Q57 = 4*

Q58 If the timing of your OFF periods were more predictable, how much would that lessen their impact on your life?

- ☐ Very much (1)
  - ☐ Somewhat (2)
  - ☐ Neutral (3)
  - ☐ Not at all (4)
- 

Q59 Do you currently keep track of your OFF periods using a paper or electronic record?

- ☐ Yes (1)
  - ☐ No (2)
- 

*Display This Question:*

*If Q59 = 1*

Q60 How do you keep track of your OFF periods? (Select all that apply)

- ☐ Paper record (1)
  - ☐ Electronic diary (2)
  - ☐ Wearable device (3)
  - ☐ Other method (please specify): (4)
- 

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**Q61 PERSONAL IMPACT OF OFF PERIODS**

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Q62 Please check all of the symptoms that you experience during OFF periods in the table below.

	Yes (1)	No (2)	Unsure (3)
Fatigue (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sleepiness (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tremor (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Stiffness (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Slowness of movement (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Change in gait/walking (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Increased falls (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulty with hand coordination (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulty swallowing (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulty speaking (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Trouble breathing (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nausea (12)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pain (13)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Anxiety (14)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Irritability (15)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Agitation or restlessness (16)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Loss of motivation (17)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sadness/depression (18)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social withdrawal (19)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How flashes (20)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sweating (21)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Loss of appetite (22)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Change in bladder function (e.g., urgency, incontinence) (23)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulty thinking (24)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: PwP 1

Start of Block: PwP 2

Q63 Please rate the impact of  $\text{\$}\{\text{Im}://\text{Field}/1\}$  during your OFF periods on your daily life.

	1 (No impact) (1)	2 (2)	3 (3)	4 (4)	5 (Severe impact) (5)
$\text{\$}\{\text{Im}://\text{Field}/1\}$ (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: PwP 2

Start of Block: PwP 3

Q64

Are there **other** symptoms not previously listed that you experience during OFF periods?

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

Display This Question:

If Q64 = 1

Q65 If yes, please specify what symptoms.

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End of Block: PwP 3

Start of Block: PwP 4

Display This Question:

If Q64 = 1

Q66 Please rate the impact of  $\{Q65/ChoiceTextEntryValue\}$  experienced during OFF periods by the person you care for with Parkinson's disease.

	1 (No impact) (1)	2 (2)	3 (3)	4 (4)	5 (Severe impact) (5)
$\{Q65/ChoiceTextEntryValue\}$ (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: PwP 4

Start of Block: PwP 5

Q67 In general, how much impact do the OFF periods have on your daily life?

- ☐ 1 (No impact) (1)
  - ☐ 2 (2)
  - ☐ 3 (3)
  - ☐ 4 (4)
  - ☐ 5 (Severe impact) (5)
-

Q68 How much are each of the following aspects of YOUR life impacted by OFF periods?

	1 (No impact) (1)	2 (2)	3 (3)	4 (4)	5 (Severe impact) (5)
Physical activity (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Leisure/hobbies (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Employment (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Relationship to carepartner (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Friendships (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Household tasks (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Driving (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Self- care/grooming (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Independence (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Communication (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your freedom to leave the home (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Scheduled activities (12)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Q69 Using a scale from 1 to 5 (where 1=Strongly Disagree and 5=Strongly Agree) please rate your level of agreement with the following statements:

	1 (Strongly disagree) (1)	2 (2)	3 (3)	4 (4)	5 (Strongly agree) (5)
Off periods frustrate me (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Off periods make me anxious (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having OFF periods is scary (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having OFF periods has hurt my self esteem (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
OFF periods make me feel embarrassed (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page Break

## Q70 EDUCATION ABOUT OFF PERIODS

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Q71 How did you learn about OFF periods? (Select all that apply)

- ☐ My doctor had previously told me about them (1)
  - ☐ My doctor explained that they were OFF periods after I brought up the symptoms (2)
  - ☐ My care partner/family explained it to me\ (3)
  - ☐ I read about them online (4)
  - ☐ I read a book about Parkinson's disease that explained what these symptoms were (5)
  - ☐ My PD support group told me what was happening (6)
  - ☐ I learned about it from a friend (7)
  - ☐ Other, please specify: (8)
- 

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*Display This Question:*

*If Q71 = 4*

Q72 Which online source?

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*Display This Question:*

*If Q71 = 5*

Q73 Which book?

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Q74 Do you feel that you have had adequate education about OFF periods? (e.g. teaching from your doctor, or educational material made available to you)

☐ Yes (1)

☐ No (2)

Q75 What would be your preferred format for learning about OFF periods?

☐ Explanation from the doctor (1)

☐ Written handout or pamphlet (2)

☐ Explanation from the doctor + written handout (3)

☐ On-line video tutorial (4)

☐ On-line written material (5)

☐ Other, please specify: (6) \_\_\_\_\_

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**Q76 COMMUNICATION REGARDING OFF PERIODS**

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Q77 The following questions relate to communication about OFF periods with the doctor who takes care of most of the Parkinson's disease-related issues.

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Q78 What type of doctor primarily cares for your Parkinson's disease?

- ☐ Movement Disorder specialist (1)
  - ☐ General neurologist (2)
  - ☐ Primary care physician (3)
  - ☐ Geriatrician (4)
  - ☐ Other (5)
  - ☐ I don't know (6)
- 

Q79 Do you discuss your OFF periods with this doctor at most (>50%) of the visits?

- ☐ Yes (1)
  - ☐ No (2)
- 

*Display This Question:*

*If Q79 = 1*

Q80 What aspects of OFF periods are discussed at most visits?

	Yes (1)	No (2)
Frequency (1)	<input type="radio"/>	<input type="radio"/>
Motor symptoms (e.g., tremor, stiffness, slowness of movement) (2)	<input type="radio"/>	<input type="radio"/>
Emotional symptoms (e.g., anxiety, depression) (3)	<input type="radio"/>	<input type="radio"/>
Symptoms of bodily function (e.g., urinary symptoms, sweating, hot flashes) (4)	<input type="radio"/>	<input type="radio"/>
Timing of OFF periods (5)	<input type="radio"/>	<input type="radio"/>
Impact of OFF periods on your life (6)	<input type="radio"/>	<input type="radio"/>
Management of OFF periods (7)	<input type="radio"/>	<input type="radio"/>

Q81 When you are in the doctor's office, how often do you actually use the phrase 'OFF period(s)' when talking about the symptoms that you experience?

- ☐ Never (1)
- ☐ Rarely (2)
- ☐ Sometimes (3)
- ☐ Often (4)
- ☐ Always (5)

Q82 Does your doctor ask about what times of the day you take your Parkinson's medication?

☐ Yes (1)

☐ No (2)

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*Display This Question:*

*If Q82 = 1*

Q83 Why do you think your doctor is interested in medication timing?

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Q84 Using a scale from 1 to 7 (where 1=Strongly Disagree and 5=Strongly Agree) please rate your level of agreement with the following statements.

	1 (Strongly Disagree) (1)	2 (2)	3 (3)	4 (4)	5 (Strongly Agree) (5)
I have difficulty discussing OFF periods with my doctor because I do not feel that he/she listens to what I have to say (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have difficulty discussing OFF periods with my doctor because he/she is distracted by the computer/other technology during our clinic visits (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have difficulty discussing OFF periods with my doctor due to lack of time at visits (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have difficulty discussing OFF periods with my doctor because we do not use the same language to describe the issues (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have difficulty discussing OFF periods with the doctor because they	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

are difficult to describe (5)

I am reluctant to tell my doctor how my OFF periods are really impacting me/us because I do not want to admit how much there are affecting me/us (6)

I am reluctant to tell my doctor how my OFF periods are really impacting me/us because I do not want my doctor to think I am complaining (7)

I am reluctant to tell my doctor about my OFF periods because I see it as a sign of progression of Parkinson's disease (8)

I am reluctant to tell the doctor about my OFF periods because they are variable/not consistent (9)



I am  
embarrassed  
to admit that I  
experience  
OFF periods  
(10)

☐☐☐☐☐

I don't think to  
discuss OFF  
periods  
because I  
consider it as  
part of the life  
of a PD patient  
(11)

☐☐☐☐☐

I forget to  
discuss OFF  
periods at my  
doctors' visits  
(12)

☐☐☐☐☐

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Q85 Do you feel that your doctor understands the burden, or impact, of OFF periods on the daily activities you have listed above?

☐ Yes (1)

☐ No (2)

☐ I don't know (3)

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Q86 Using the table below please indicate what strategies would help you to discuss OFF periods with your doctors.

	I have used this and it is helpful (1)	I think this would be helpful if I tried it (2)	This would not be helpful (3)
Having longer doctor visits (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having a free-flowing conversation with the doctor (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Writing down a problem list/agenda to discuss with the doctor prior to visits (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Answering a questionnaire about OFF symptoms at my doctor visits (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Keeping a diary of my OFF periods and medication timing prior to clinic visits (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having a wearable device record OFF periods automatically and transmit this information to my doctor (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sharing a video of my OFF periods with my doctor at the visit (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having a partner at the visit to help describe the OFF periods (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other, please specify: (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Q87 Have you communicated with your doctor between scheduled visits about your OFF periods?

- ☐ No, it has not been necessary (1)
- ☐ No, I would have liked to but the doctor is not available. (2)
- ☐ No, I would have liked to but I avoid bothering my doctor (3)
- ☐ Yes (4)

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*Display This Question:*

*If Q87 = 4*

Q88 Has this been important to you?

- ☐ Yes (1)
- ☐ Somewhat (2)
- ☐ No (3)

Q89 Have you found any communication tools about OFF periods that you have found helpful?

- ☐ Yes (1)
- ☐ No (2)

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*Display This Question:*

*If Q89 = 1*

Q90 Please describe and specify source.

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End of Block: PwP 5

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Start of Block: CP 1

Q4 When a person with Parkinson's disease benefits from medication, over time they can begin to experience periods where the medications don't work or don't work as well. In those periods those symptoms that are typically improved by the medication temporarily worsen. These periods are called **OFF periods**.

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Q5 Does the person you care for with Parkinson's disease experience OFF periods, as just defined?

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

Skip To: End of Survey If Q5 = 2

Skip To: End of Survey If Q5 = 3

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Q6 Are you familiar with the term "OFF" or "OFF periods" related to Parkinson's disease, as defined below?

*When a person with Parkinson's disease benefits from medication, over time they can begin to experience periods where the medications don't work or don't work as well. In those periods those symptoms that are typically improved by the medication temporarily worsen. These periods are called **OFF periods**.*

- ☐ Yes (1)
- ☐ No (2)
- 

Page Break

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## Q7 PERSONAL EXPERIENCE OF OFF PERIODS

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Q8 How long has the person you care for had Parkinson's disease (in years)?

- ☐ 1-5 (1)
  - ☐ 6-10 (2)
  - ☐ 11-15 (3)
  - ☐ 16-20 (4)
  - ☐ Greater than 20 (5)
  - ☐ I don't know (6)
- 

Q9 How many years ago did the person you care for with Parkinson's disease begin to experience OFF periods?

- ☐ Less than 1 year (1)
- ☐ 1-5 years (2)

Q8 = 2

Or Q8 = 3

Or Q8 = 4

Or Q8 = 5

- ☐ 6-10 years (3)

*Invalid Logic Click Here to Edit Logic*

- ☐ Greater than 10 years (4)
  - ☐ I don't know (5)
-

Q10 Over the last week, on average how many OFF periods does the person you care for experience in a typical waking day?

- ☐ No periods, zero (1)
  - ☐ 1 period per day (2)
  - ☐ 2 periods per day (3)
  - ☐ 3 periods per day (4)
  - ☐ 4 periods per day (5)
  - ☐ Greater than 4 periods per day (6)
  - ☐ I don't know (7)
- 

Q11 Over the last week, on average what is the typical duration of each OFF period?

- ☐ Less than 15 minutes (1)
  - ☐ Between 15 minutes and 30 minutes (2)
  - ☐ Between 30 minutes and 45 minutes (3)
  - ☐ Between 45 minutes and 1 hour (4)
  - ☐ Between 1 hour and 2 hours (5)
  - ☐ Greater than 2 hours (6)
  - ☐ I don't know (7)
-

Q12 What proportion of the OFF periods come at unpredictable (i.e. unexpected) times?

- ☐ 0% (1)
- ☐ Less than 25% (2)
- ☐ 25-50% (3)
- ☐ Greater than 50% (4)
- ☐ I don't know (5)

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*Display This Question:*

*If Q12 = 2*

*Or Q12 = 3*

*Or Q12 = 4*

Q13 If the timing of the OFF periods were more predictable , how much would that lessen their impact on your life?

- ☐ Very much (1)
- ☐ Somewhat (2)
- ☐ Neutral (3)
- ☐ Not at all (4)

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Q14 Do you currently help the person you care for (who has Parkinson's disease) keep track of his or her OFF periods using a paper or electronic record?

- ☐ Yes (1)
  - ☐ No (2)
-

*Display This Question:*

*If Q14 = 1*

Q15 How do you keep track of OFF periods? (Select all that apply)

☐

Paper record (1)

☐

Electronic diary (2)

☐

He or she has a wearable device that I help manage (3)

☐

Other, please specify: (4)

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Q16 Check all of the symptoms of OFF periods experienced by the person you care for with Parkinson's disease.

	Yes (1)	No (2)	Unsure (3)
Fatigue (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sleepiness (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tremor (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Stiffness (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Slowness of movement (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Change in gait/walking (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Increased falls (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulty with hand coordination (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulty swallowing (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulty speaking (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Trouble breathing (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nausea (12)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pain (13)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Anxiety (14)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Irritability (15)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Agitation or restlessness (16)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Loss of motivation (17)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sadness/depression (18)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social withdrawal (19)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How flashes (20)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sweating (21)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Loss of appetite (22)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Change in bladder function (e.g., urgency, incontinence) (23)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulty thinking (24)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: CP 1

Start of Block: CP 2

Q17 Please rate the impact of  $\text{\$}\{\text{Im}://\text{Field}/1\}$  experienced during OFF periods on your daily life (as the care partner).

	1 (No impact) (1)	2 (2)	3 (3)	4 (4)	5 (Severe impact) (5)
$\text{\$}\{\text{Im}://\text{Field}/1\}$ (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: CP 2

Start of Block: CP 3

Q18

Are there **other** symptoms not previously listed that the person you care for with Parkinson's experiences during OFF periods?

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

*Display This Question:*

*If Q18 = 1*

Q19 If yes, please specify what symptoms.

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End of Block: CP 3

Start of Block: CP 4

*Display This Question:*

*If Q18 = 1*

Q20 Please rate the impact of  $\{Q19/ChoiceTextEntryValue\}$  experienced during OFF periods on your daily life (as the care partner).

	1 (No impact) (1)	2 (2)	3 (3)	4 (4)	5 (Severe impact) (5)
$\{Q19/ChoiceTextEntryValue\}$ (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: CP 4

**Q21 PERSONAL IMPACT OF OFF PERIODS**

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**Q22 These questions are asking how the OFF times impact *your* life. Please answer these questions with respect to the impact on you, not the person with Parkinson's disease.**

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**Q23 In general, how much impact do the OFF periods have on YOUR daily life?**

- ☐ 1 (No impact) (1)
  - ☐ 2 (2)
  - ☐ 3 (3)
  - ☐ 4 (4)
  - ☐ 5 (Severe impact) (5)
-

Q24 How much are each of the following aspects of YOUR life impacted by OFF periods ?

	1 (No impact) (1)	2 (2)	3 (3)	4 (4)	5 (Severe impact) (5)
Your Leisure/hobbies (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your Employment (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your relationship to the person with Parkinson's disease (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your Friendships (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your Household tasks (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your Mood (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your Self-care (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your Physical Health (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your freedom to leave the home (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Scheduled activities (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Q25 Does the person that you care for with Parkinson's disease rely on you for timely administration of medication?

☐ Yes (1)

☐ No (2)

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*Display This Question:*

*If Q25 = 1*

Q26 Please rate the impact of being relied on for timely administration of medication on your life.

☐ 1 (No impact) (1)

☐ 2 (2)

☐ 3 (3)

☐ 4 (4)

☐ 5 (Severe impact) (5)

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Q27 Using a scale from 1 to 5 (where 1=Strongly Disagree and 5=Strongly Agree) please rate your level of agreement with the following statements.

	1 (Strongly Disagree) (1)	2 (2)	3 (3)	4 (4)	5 (Strongly Agree) (5)
The OFF periods frustrate me (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The OFF periods make me anxious (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Watching OFF periods is scary (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The OFF periods make me feel embarrassed (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page Break

## Q28 EDUCATION ABOUT OFF PERIODS

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Q29 How did you learn about OFF periods? (Select all that apply)

- ☐ The doctor of the person I care for had told me about them before the person I care for began to experience them (1)
- ☐ The doctor of the person I care for explained that they were OFF periods after I brought up the symptoms (2)
- ☐ The person I care for explained it to me (3)
- ☐ I read about them on-line (4)
- ☐ I read a book about Parkinson's disease that explained what these symptoms were (5)
- ☐ The Parkinson's disease support group told me what was happening (6)
- ☐ I learned about it from a friend (7)
- ☐ Other, please specify: (8)
- 

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*Display This Question:*

*If Q29 = 4*

Q30 Which online source?

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*Display This Question:*

*If Q29 = 5*

Q31 Which book?

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Q32 Do you feel that you have had adequate education about OFF periods? (e.g. teaching from your doctor, or educational material made available to you)

☐ Yes (1)

☐ No (2)

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Q33 What would be your preferred format for learning about OFF periods?

- ☐ Explanation from the doctor (1)
  - ☐ Written handout or pamphlet (2)
  - ☐ Explanation from the doctor + written handout (3)
  - ☐ On-line video tutorial (4)
  - ☐ On-line written material (5)
  - ☐ Other, please specify: (6) \_\_\_\_\_
- 

Q34

Do you think it is helpful to learn about OFF periods early in the course of Parkinson's disease, before they are experienced?

- ☐ Yes (1)
  - ☐ No (2)
- 

Page Break

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**Q35 COMMUNICATION REGARDING OFF PERIODS**

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Q36 The following questions relate to communication about OFF periods with the doctor who takes care of most of the Parkinson's disease-related issues.

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Q37 What type of doctor primarily cares for the person's Parkinson's disease?

- ☐ Movement Disorder specialist (1)
  - ☐ General neurologist (2)
  - ☐ Primary care physician (3)
  - ☐ Geriatrician (4)
  - ☐ Other (5)
  - ☐ I don't know (6)
- 

Q38 Do you attend appointments with the person who has Parkinson's disease?

- ☐ Yes (1)
- ☐ No (2)
- ☐ Sometimes (3)

*Skip To: End of Block If Q38 = 2*

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Q39 How important do you feel it is for you as a caregiver to attend the appointments so that you can provide information to the doctor about the OFF periods? (e.g. the frequency, duration or impact of the OFF periods)

	1 (Not important) (1)	2 (2)	3 (3)	4 (4)	5 (Very important) (5)
(1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q40 What aspects of OFF periods are discussed at most visits?

	Yes (1)	No (2)
Frequency (1)	<input type="radio"/>	<input type="radio"/>
Motor symptoms (e.g., tremor, stiffness, slowness of movement) (2)	<input type="radio"/>	<input type="radio"/>
Emotional symptoms (e.g., anxiety) (3)	<input type="radio"/>	<input type="radio"/>
Symptoms of bodily function (e.g., urinary symptoms, sweating, hot flashes) (4)	<input type="radio"/>	<input type="radio"/>
Timing of OFF periods (5)	<input type="radio"/>	<input type="radio"/>
Impact of OFF periods on the life of the person you care for (6)	<input type="radio"/>	<input type="radio"/>
Impact of OFF periods on YOUR life (7)	<input type="radio"/>	<input type="radio"/>
Management of OFF periods (8)	<input type="radio"/>	<input type="radio"/>

Q41 When you are in the doctor's office, how often do you actually use the phrase "OFF period(s)" when talking about the symptoms that the person you care for experiences?

- ☐ Never (1)
- ☐ Rarely (2)
- ☐ Sometimes (3)
- ☐ Often (4)
- ☐ Always (5)

Q42 Does the doctor ask about the timing of medication (e.g., levodopa/carbidopa) at every, or almost every, visit?

- ☐ Yes (1)
- ☐ No (2)

*Display This Question:*

*If Q42 = 1*

Q43 Why do you think your doctor is interested in medication timing?

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Q44 Using a scale from 1 to 5 (where 1=Strongly Disagree and 5=Strongly Agree) please rate your level of agreement with the following statements.

	1 (Strongly disagree) (1)	2 (2)	3 (3)	4 (4)	5 (Strongly agree) (5)
I have difficulty discussing OFF periods with the doctor because I do not feel that he/she listens to what I have to say (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have difficulty discussing OFF periods with the doctor because he/she is distracted by the computer/other technology during our clinic visits (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have difficulty discussing OFF periods with the doctor due to lack of time at visits (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have difficulty discussing OFF periods with the doctor because we do not use the same language to describe the issues (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have difficulty discussing OFF periods with the doctor because they	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

are difficult to describe (5)

I am reluctant to tell the doctor how his or her OFF periods are really impacting me/us because I do not want to admit how much they are affecting me/us (6)

I am reluctant to tell the doctor about his or her OFF periods because I see it as a sign of progression of Parkinson's disease (7)

I am reluctant to tell the doctor how his or her OFF periods are really impacting me/us because I do not want the doctor to think I am complaining (8)

I am reluctant to tell the doctor about the OFF periods because they are variable/not

☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

consistent (9) |

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Q45 Do you feel that the doctor understands the burden, or impact, of OFF periods on the daily activities you have listed above?

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

Q46 Using the table below please indicate what strategies would help you to discuss OFF periods with the doctor.

	I have used this and it is helpful (1)	I think this would be helpful if I tried it (2)	This would not be helpful (3)
Having longer clinic visits (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having a free-flowing conversation with the doctor (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Writing down a problem list/agenda to discuss with the doctor prior to visits (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Answering a questionnaire about OFF symptoms at the clinic visit (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Keeping a diary of OFF periods and medication timing prior to clinic visits (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sharing a video of OFF periods with my doctor at the visit (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having a wearable device record OFF periods automatically and transmit this information to the doctor (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other, please specify: (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: CP 5

Start of Block: CP 6

Q47 Have you communicated with the doctor between scheduled visits about OFF periods?

- ☐ No, it has not been necessary (1)
- ☐ No, I would have liked to but the doctor is not available (2)
- ☐ No, I would have liked to but I avoid bothering the doctor (3)
- ☐ Yes (4)
- ☐ Not applicable - I am not the person who would communicate with the doctor (5)

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*Display This Question:*

*If Q47 = 4*

Q48 Has this been important to you?

- ☐ Yes (1)
- ☐ Somewhat (2)
- ☐ No (3)

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Q49 Have you found any communication tools about OFF periods that you have found helpful?

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End of Block: CP 6

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