

# Understanding OFF and ON in Parkinson's Patients

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Start of Block: Introduction

## QID18 Understanding OFF and ON in Parkinson's Patients

The Michael J. Fox Foundation for Parkinson's Research seeks to understand unmet needs of Parkinson's patients. With this goal, the current research explores how patients experience, and communicate about, their life with Parkinson's disease (PD). In particular, the current research focuses on OFF and ON periods in PD.

End of Block: Introduction

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Start of Block: Experience OFF?

QID51 Based on the above definition of OFF, do you experience OFF periods?

☐ Yes (1)

☐ No (2)

*Skip To: End of Survey If QID51 = 2*

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End of Block: Experience OFF?

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Start of Block: Lexicon 1

QID3 In the space provided below please describe your *experience when you are OFF*.

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Page Break

End of Block: Lexicon 1

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Start of Block: Lexicon 2

QID6 When you talk with your family and friends, what do you call the periods where your PD symptoms return?

- ☐ OFF Periods (1)
  - ☐ OFF Episodes (2)
  - ☐ OFF Time (3)
  - ☐ Something Else (PLEASE SPECIFY) (4)
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Page Break

End of Block: Lexicon 2

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Start of Block: PD symptoms and Impact of PD on Quality of Life 1

QID8 Thinking about all of the different types of symptoms you experience when OFF, including physical, emotional and intellectual/mental, what are the top three **most bothersome** for you?

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QID9 How often do your OFF periods have a predictable relationship with the timing of your medication? Some examples of predictable relationships would be: OFF periods that are more common just before you are due to take more medication, just after, or at a consistent time point in the middle of your medication cycle.

- ☐ Always (1)
- ☐ Most of the time (2)
- ☐ Sometimes (3)
- ☐ Rarely (4)
- ☐ Never (5)

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Page Break

QID19 How often are your OFF periods unpredictable? Unpredictable means they happen “out of nowhere” – even during a typical time your medication dose is usually effective.

- ☐ Always (1)
- ☐ Most of the time (2)
- ☐ Sometimes (3)
- ☐ Rarely (4)
- ☐ Never (5)

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Page Break

QID10 Are there triggers, such as anxiety or stress, which can bring on an OFF period for you?

☐ Yes (1)

☐ No (2)

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*Display This Question:*

*If QID10 = 1*

QID11 What are those triggers?

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QID52 In a typical 24-hour period, for how many **hours** are you awake? Please include both the hours you are awake during the day and night. For example, if you are awake 14 hours a day, please enter 14 in the text box below.

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QID53 And, in a typical day, how many hours are you OFF?

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QID20 How often does taking your PD medication resolve your OFF symptoms?

- ☐ Always (1)
- ☐ Most of the time (2)
- ☐ Sometimes (3)
- ☐ Rarely (4)
- ☐ Never (5)

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QID21 How often does taking your PD medication NOT resolve your OFF symptoms?

- ☐ Always (1)
- ☐ Most of the time (2)
- ☐ Sometimes (3)
- ☐ Rarely (4)
- ☐ Never (5)

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Page Break

QID15 Other than taking medication, is there anything you do during your OFF periods to help manage your PD symptoms?

☐ Yes (1)

☐ No (2)

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Page Break

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Display This Question:

If QID15 = 1

QID16 Other than taking medication, what do you do during your OFF periods to help manage your PD symptoms?

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End of Block: PD symptoms and Impact of PD on Quality of Life 2

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Start of Block: Seven Phrases- Pre Metaphor

QID49 Now we will present seven phrases. For each phrase, we would like to know whether the phrase describes how you have ever felt in an OFF period.

End of Block: Seven Phrases- Pre Metaphor

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Start of Block: Metaphors 1



QID22 Does the following phrase describe how you have ever felt in an OFF period?

*Like the tin man in Wizard of Oz*

☐ Yes (1)

☐ No (2)

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Page Break



QID23 Does the following phrase describe how you have ever felt in an OFF period?

*Sinking slowly into quicksand*

☐ Yes (1)

☐ No (2)

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Page Break



QID24 Does the following phrase describe how you have ever felt in an OFF period?

*A concrete suit coming on*

☐ Yes (1)

☐ No (2)

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Page Break





QID25 Does the following phrase describe how you have ever felt in an OFF period?

*Cloudy thought process*

☐ Yes (1)

☐ No (2)

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Page Break



QID26 Does the following phrase describe how you have ever felt in an OFF period?

*Trapped in my own skin*

☐ Yes (1)

☐ No (2)

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Page Break



QID27 Does the following phrase describe how you have ever felt in an OFF period?

*Walking through mud*

☐ Yes (1)

☐ No (2)

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Page Break



QID28 Does the following phrase describe how you have ever felt in an OFF period?  
*In another world*

☐ Yes (1)

☐ No (2)

End of Block: Metaphors 1

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Start of Block: Metaphors 2

QID29 Is there any other phrase you use to describe your OFF experience?

☐ Yes (1)

☐ No (2)

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Display This Question:

If QID29 = 1

QID30 Please specify the other phrase(s) you use to describe your OFF experience.

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End of Block: Metaphors 2

Start of Block: ON Symptoms

QID41 Now, we will focus on ON periods. As a reminder, we refer to periods during which symptoms are better controlled with medications as ON periods. In some people, during ON periods, involuntary movements called dyskinesias occur. **Dyskinesias** are uncontrolled, jerky, writhing or dance-like movements. They may feel or look like fidgeting, head bobbing, or like the body is rocking back and forth. These can affect the arms, legs or torso and can occur in one part of your body or throughout.

Do you experience bothersome involuntary movements such as dyskinesias when in an ON period?

☐ Yes (1)

☐ No (2)

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Display This Question:

If QID41 = 1

QID42 Please describe your experience with ON period **dyskinesias**.

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End of Block: ON Symptoms

Start of Block: Demographics

QID55 Now, we just have a few more questions for clarification purposes.

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QID44 What medication(s) are you currently taking for your Parkinson's Disease? Please select all that apply.

- ☐ Carbidopa-Levodopa (Sinemet, Sinemet CR, Sinemet Extended Release, Parcopa, Rytary, Stalevo, Duopa) (23)
- ☐ Entacapone (Comtan) (24)
- ☐ Pramipexole (Mirapex or Mirapex ER) (25)
- ☐ Ropinirole (Requip or Requip XL) (26)
- ☐ Rotigotine (Neupro patch) (27)
- ☐ Apomorphine (apokyn) (28)
- ☐ Amantadine (Symmetrel or Gocovri) (29)
- ☐ Safinamide (Xadago) (30)
- ☐ Selegiline (Deprenyl, Eldepryl, Zelapar) (31)
- ☐ Take medication for Parkinson's Disease, but none of the medications listed above (Please specify) (32) \_\_\_\_\_
- ☐ Do not take any medication for Parkinson's Disease (33)

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Page Break \_\_\_\_\_

*Display This Question:*

*If QID44 != 33*

QID56 How many times per day do you take medication(s) for your Parkinson's disease? For example, if you take two pills in one day at the same time, please count that as 'once a day'. If you take 1 pill in the morning and 1 pill in the evening, please count that as '2 times a day'.

- ☐ Once a day (1)
- ☐ 2 times a day (2)
- ☐ 3 times a day (3)
- ☐ 4 times a day (4)
- ☐ 5 or more times a day (5)

**End of Block: Demographics**

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**Start of Block: WOQ 19**



QID1 Tick the box where applicable.

***The following symptoms have occurred at least once a day recently.***

	Yes (1)	No (2)
Tremors (1)	<input type="radio"/>	<input type="radio"/>
Difficulty speaking (2)	<input type="radio"/>	<input type="radio"/>
Anxiety (3)	<input type="radio"/>	<input type="radio"/>
Sweating (4)	<input type="radio"/>	<input type="radio"/>
Mood swings or depression (5)	<input type="radio"/>	<input type="radio"/>
Feeling weak (6)	<input type="radio"/>	<input type="radio"/>
Impaired balance (7)	<input type="radio"/>	<input type="radio"/>
Slow movemnt (8)	<input type="radio"/>	<input type="radio"/>
Difficulty doing detailed work with hands and fingers (9)	<input type="radio"/>	<input type="radio"/>
Numbness (10)	<input type="radio"/>	<input type="radio"/>
Stiffness of body parts (11)	<input type="radio"/>	<input type="radio"/>
Feelings of panic (12)	<input type="radio"/>	<input type="radio"/>
Confusion or slow thinking (13)	<input type="radio"/>	<input type="radio"/>
Abdominal discomfort (14)	<input type="radio"/>	<input type="radio"/>
Muscle spasms (15)	<input type="radio"/>	<input type="radio"/>

Difficulty standing from a chair  
(16)

☐☐

Hot-flashes and chills in the  
body (17)

☐☐

Sharp pain (18)

☐☐

Persistent dull pain (19)

☐☐

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QID2 Tick the box where applicable.

***After taking levodopa\* or other Parkinson's medication the symptom...***

\* Medications that contain levodopa include: Carbidopa/Levodopa, Parcopa, Sinemet, Rytary, Stalevo

	is alleviated (1)	remains the same (2)
Tremors (1)	<input type="radio"/>	<input type="radio"/>
Difficulty speaking (2)	<input type="radio"/>	<input type="radio"/>
Anxiety (3)	<input type="radio"/>	<input type="radio"/>
Sweating (4)	<input type="radio"/>	<input type="radio"/>
Mood swings or depression (5)	<input type="radio"/>	<input type="radio"/>
Feeling weak (6)	<input type="radio"/>	<input type="radio"/>
Impaired balance (7)	<input type="radio"/>	<input type="radio"/>
Slow movemnt (8)	<input type="radio"/>	<input type="radio"/>
Difficulty doing detailed work with hands and fingers (9)	<input type="radio"/>	<input type="radio"/>
Numbness (10)	<input type="radio"/>	<input type="radio"/>
Stiffness of body parts (11)	<input type="radio"/>	<input type="radio"/>
Feelings of panic (12)	<input type="radio"/>	<input type="radio"/>
Confusion or slow thinking (13)	<input type="radio"/>	<input type="radio"/>
Abdominal discomfort (14)	<input type="radio"/>	<input type="radio"/>

Muscle spasms (15)	<input type="radio"/>	<input type="radio"/>
Difficulty standing from a chair (16)	<input type="radio"/>	<input type="radio"/>
Hot-flashes and chills in the body (17)	<input type="radio"/>	<input type="radio"/>
Sharp pain (18)	<input type="radio"/>	<input type="radio"/>
Persistent dull pain (19)	<input type="radio"/>	<input type="radio"/>

End of Block: WOQ 19

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