



SPEAKING UP ABOUT OFF PERIODS

*A doctor discussion
guide for people living
with Parkinson's*

Actor portrayal

What exactly are OFF periods?

OFF periods are when Parkinson's symptoms return between regular doses of carbidopa/levodopa.

Many people with Parkinson's have OFF periods.

This guide will help you understand OFF periods and how to talk about them.

Some OFF period symptoms can be difficult to notice and talk about.

Keep in mind that OFF periods may include:

- Motor symptoms like stiffness or shaking
- Nonmotor symptoms like anxiety or fatigue

Some questions you might have about OFF periods

Q. What should I tell my doctor if I think I'm having OFF periods?

A. Tell your doctor as many details as you can about the symptoms you have between your regular doses of Parkinson's medicine. Remember, you may not have OFF period symptoms during your doctor visit.

Q. How many people with Parkinson's have OFF periods?

A. Of the nearly 1 million people with Parkinson's in the United States, about 40% will have OFF periods within 5 years of starting treatment.

Are you experiencing OFF periods?

Symptoms can vary from person to person and from OFF period to OFF period. Nobody knows your OFF periods better than you.

Now think about your own experience with Parkinson's, and fill out the OFF symptom checklist.

OFF periods can include the return of motor symptoms (related to movement) or nonmotor symptoms (unrelated to movement).

WHICH SYMPTOMS DO YOU EXPERIENCE?

Motor symptoms	Fill in time(s) of day	Nonmotor symptoms	Fill in time(s) of day
<input type="radio"/> Shaking or tremor		<input type="radio"/> Anxiety/panic attacks	
<input type="radio"/> Slowness of movement		<input type="radio"/> Drenching sweats	
<input type="radio"/> Problems with balance		<input type="radio"/> Difficulty thinking	
<input type="radio"/> Challenges with hand movements		<input type="radio"/> Fatigue or drowsiness	
<input type="radio"/> Speech difficulties		<input type="radio"/> Restlessness	
<input type="radio"/> Stiffness		<input type="radio"/> Irritability	
<input type="radio"/> Difficulty getting out of a chair		<input type="radio"/> Sleep disturbances	
<input type="radio"/> Other _____		<input type="radio"/> Other _____	

There are a few more details your doctor may need to know. Answer the questions on these pages.

On an average day, how many OFF periods (the return of Parkinson's symptoms) do you have?

- None
- 1-2
- 3-5
- More than 5

On most days, how much time do you spend in OFF periods?

- None
- Less than 1 hour
- 1-2 hours
- 3-5 hours
- More than 5 hours

Sometimes it's difficult to realize if you're having OFF periods. Think about the activities you enjoy. Have you been having symptoms that you notice when doing these things?



Notes

A great doctor visit is when:

A little planning can go a long way. This section will help you prepare for your next doctor visit.

Recent changes that I've noticed:

The last time we met, I remember that my doctor told me:

Here are some things I want to remember to bring up at my next visit:

Use these pages to remind yourself of important details you'd like to share.

My next doctor appointment is

(date)

If you think you may be experiencing symptoms of OFF periods, speak up at your next doctor visit. The more you share, the more your doctor may be able to help.

**Ask about treatment options
for OFF periods.**



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