



Is it time to
talk about
“off” time?

You shouldn't have to settle for a medication that wears off quickly. Educate yourself with the enclosed information and then talk to your healthcare provider about your options.



Let your voice be heard.

We all have things that drive us: our passions, our pastimes, our personal goals. And when we set our mind to it—when we make what’s important a priority—new possibilities begin to unfold.

The same can be said about our health. If you advocate for yourself, ask questions, and learn all you can about your treatment options, you may be able to experience less “off” time and get back to doing more of what you enjoy.

You know your body best.

As we've learned, everyone's Parkinson's experience is so different. Symptoms can vary widely from person to person and evolve over time.

So the best way for the people in your life and your healthcare provider to understand what's happening is to tell them.

Be sure to:

- ✓ Track your symptoms and stay in tune with your overall health.
- ✓ Be open and honest with your healthcare provider about how you're doing and your treatment goals.

Helping your healthcare provider find the right treatment starts with you. If you're not satisfied with your current medication, let them know.



What your body might be trying to tell you.

When it comes to your health, it's important to listen to your body and keep track of how it behaves throughout the day—particularly when you're taking medication for your symptoms. For example, it might be helpful to track your “off” time and your “on” time.

- **“Off” time** – when your medication isn't working and your motor symptoms return
- **“On” time** – when your medication is working well to control your motor symptoms

Among people with Parkinson's disease, “off” time is quite common. One survey found that:



of people experience at least 1 “off” episode each day.



of people experience 2 or more hours of “off” time each day.



of those people said that “off” time affected their daily activities.

Given the disruptions that “off” time can cause, it can be helpful to keep track of when and how often your “off” time occurs, and even what kind of “off” time it is. For example, is it:

- **Early morning “off” time** – when you wake up, does your body respond slowly to your medication?
- **Wearing “off” time** – do the benefits of your medication wear off before it's time to take your next dose?
- **Unpredictable “off” time** – does your “off” time happen randomly, even if you've taken your medication exactly as prescribed?
- **Partial “off” time** – after you've taken your medication, do your symptoms improve only a little or not at all?

The type of “off” time you experience may be a clue for your healthcare provider as to whether you need your dose adjusted or you need a different treatment altogether.

How do you know if your current medication is working? By keeping track of how you're doing—your “on” time and your “off” time—and then communicating this to your healthcare provider. “Off” time may be a sign that it's time for a change.

You've got options.

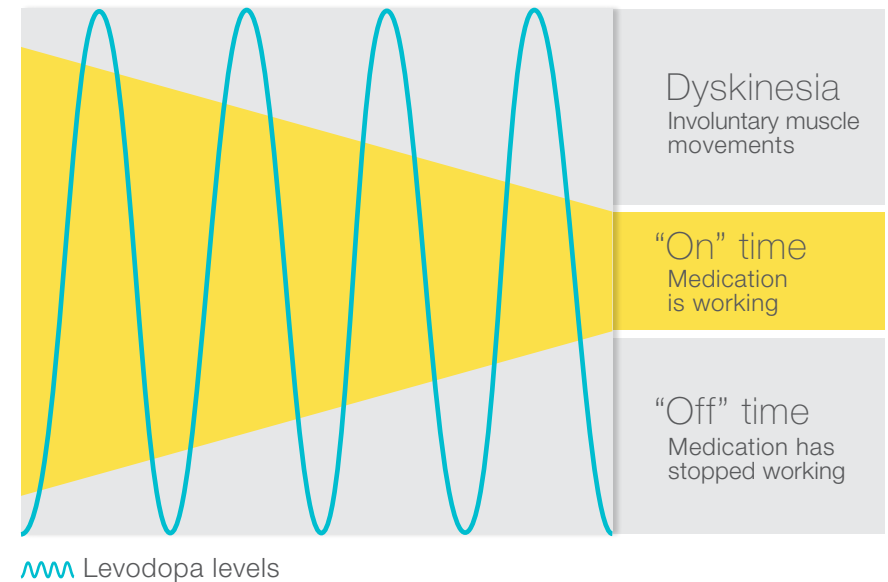
A range of medications have been developed to treat the motor symptoms (such as tremors or rigidity) associated with Parkinson's disease, including carbidopa/levodopa (CD/LD), dopamine agonists, COMT inhibitors, and MAO-B inhibitors.

CD/LD is the most commonly prescribed—as well as an effective—Parkinson's treatment, with immediate-release CD/LD being the most well-known form. But immediate-release CD/LD has its limits: while it works quickly, it may not work for very long. Also, once people have been taking it for a while, they may begin to fluctuate more quickly between periods of "on" time and "off" time.



If you're experiencing fluctuations, it may be because the window of time when it's possible for levodopa to be effective without causing side effects is narrowing, as shown in the visual below.

Over time, "on" time can be more difficult to achieve



If you're experiencing frequent "off" time, an extended-release medication that offers a more consistent, persistent delivery of levodopa may be able to help.

COMT=catechol-O-methyltransferase; MAO-B=monoamine oxidase-B.

Talking to your healthcare provider

As your healthcare provider may have shared, the goal of treatment is to reduce your “off” time so you can get back to doing more of what you enjoy. Your ideal treatment plan should be tailored to fit your needs.

Maybe you don’t want to have to manage several medications. Maybe you’re happy with immediate-release CD/LD, but just wish it would last longer. Whatever your concerns, let your voice be heard.

To help you identify what your goals are for treatment, fill out the following discussion guide, tear it out, and bring it to discuss with your doctor today.



Goals to discuss with my doctor today:

1 _____

2 _____

3 _____



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My symptoms

Do you have any new or worsening symptoms? Check all that apply.

| Motor symptoms: | New | Worse |
|-------------------------------------|-----|-------|
| Dyskinesia | | |
| Rigidity | | |
| Bradykinesia (slowness of movement) | | |
| Tremors | | |
| Difficulties with posture | | |
| Freezing of gait | | |
| Shuffling or slow walking | | |
| Reduced facial expression | | |
| Small handwriting | | |
| Voice and speech changes | | |
| Swallowing problems | | |
| Other: | | |

| Non-motor symptoms: | New | Worse |
|-------------------------------|-----|-------|
| Changes in mood and cognition | | |
| Sleep issues | | |
| Fatigue | | |
| Pain | | |
| Gastrointestinal issues | | |
| Poor bladder control | | |
| Other: | | |

My “off” time

About how many hours of “off” time do you have each day? _____

About how many times do you fluctuate between “off” and “on” time each day? _____

What kind of “off” time do you experience? Check all that apply.

- Early morning “off” time
- Unpredictable “off” time
- Wearing “off” time
- Partial “off” time

Which of the following statements best describe your experiences? Check all that apply.

- It is hard to know how my day will go because of “off” time.
- My medication doesn’t seem to be working as well as it used to.
- Each dose seems to wear off more quickly than it used to.
- “Off” time seems to happen more frequently between doses.

My treatment goals

Which of the following statements best describe your experiences with treatment? Check all that apply.

- I think I could benefit from a medication that lasts longer.
- I think that CD/LD works well; I just wish it wouldn’t wear off so quickly.
- I would prefer to not have to take multiple kinds of medication.
- I would prefer to not have to take my medication so often.
- The thought of trying something new makes me nervous.
- I am looking for a medication that can reduce my “off” time.



If “off” time is
affecting your time,
it may be time to
talk to your doctor.

