

MANAGING PARKINSON'S DISEASE

FACTS

- PD is slowly progressive and rapid changes are usually explainable by something else, such as a urinary tract infection or electrolyte abnormality.
- Be very attentive to medication administration and effects.
 - Take medication at the same time every day.
- Using a PD diary is helpful. See the website document PD diary for more information.
- Part of Taking Charge! is learning how your body responds to carbidopa-levodopa medication. There is some degree of “trial and error” that occurs with finding the RIGHT dose and the RIGHT timing.
- You CAN NOT hurt yourself or influence the progression of the disease by making incremental changes to your carbidopa-levodopa on your own.
- YOU are the best judge of when and if the carbidopa-levodopa is helping so YOU are the best person to adjust the medication. Learning how to do this will give you more control over the disease. Think of it like a person with diabetes adjusting their own insulin.
- It IS dangerous to abruptly stop carbidopa-levodopa so this should NEVER be done.
- Consult the provider if you feel the medication is not working or causing too many side effects.
 - Nausea
 - Dizziness
 - Drowsiness
 - Confusion
 - Hallucinations

HOW MOVEMENT IS AFFECTED BY PD AND CARBIDOPA-LEVODOPA

- PD causes slow and stiff movement and often tremors (rhythmic).
- Carbidopa-Levodopa (CD-LD) helps reduce tremors and makes movement more fluid, smooth and quick. Think of CD-LD as the oil can for the Tin Man in the Wizard of Oz!
- Sometimes CD-LD can cause excessive, involuntary movements like wiggling, writhing, or squirming. These movements are not rhythmic like tremors and are called dyskinesia.

TERMS FOR UNDERSTANDING MEDICATION ADJUSTMENTS

- ON - PD is well controlled and the medications are working.
 - Delayed ON
 - PD slowness, stiffness or tremors persist more than 45 minutes after taking carbidopa-levodopa.
- OFF - PD medication is not working and PD symptoms occur.
 - Wearing OFF
 - Carbidopa-levodopa loses its effectiveness before the next dose is due.
 - Early morning OFF
 - Slowness, stiffness, or tremors occur upon waking.
 - Sudden or unpredictable OFF
 - OFF period occurs randomly.

IMMEDIATE RELEASE CARBIDOPA-LEVODOPA

- The provider will give initial instructions for the dosage and the time it is to be taken.
- Continue with the prescribed dose for 7 days before making any incremental changes as described below. Be confident experimenting with the dose, such as increasing from 1 tablet each time to 1.5 or 2 tablets each time or increasing from 3 times a day to 4 times a day. You won't hurt yourself experimenting.

- You DO NOT need to report incremental changes you make to the provider UNLESS you need an earlier refill of the medication because you are using more of it than initially prescribed.

Delayed ON

- The dose that was taken does not kick in and reduce symptoms of PD within 45 minutes.
- Strategies
 - Increase the number of times per day the carbidopa-levodopa is taken by one
 - For example, the carbidopa-levodopa is being taken at 7am, 3pm and 11pm. The 3pm dose does not kick in until 4pm. The next day, take the carbidopa-levodopa at 7am, 11pm, 3pm, 7pm and 11pm
 - Use the PD log at the end of this document to track times medication is taken and when symptoms occur. This will help create a clear picture of how your body is responding to the medication.
 - A second strategy is to keep the timing the same but increase the amount of carbidopa-levodopa taken at each dose by ½ to 1 tablet. Either strategy can work.
 - Pay attention to whether a meal or certain foods block the effect of CD-LD. If it does, take the medicine 30 minutes prior to a meal or 1 hour afterward.

Wearing OFF

- The dose that was taken wears off before the next dose is due.
- Strategies
 - Shorten the time interval between doses which may increase the number of doses taken during the day
 - For example, the carbidopa-levodopa is being taken at 7am, 3pm and 11pm. The medicine wears off around noon and 8pm. The next day, take the carbidopa-levodopa at 7am, 11pm, 3pm, 7pm and 11pm

- Use the PD diary at the end of this document to track times medication is taken and when symptoms occur. This will help create a clear picture of how your body is responding to the medication.
- A second strategy is to keep the timing the same but increase the amount of carbidopa-levodopa taken at each dose by ½ to 1 tablet.
- Either strategy can be effective and sometimes a combination of both is necessary. Remember that trial and error is part of managing symptoms.

Early Morning OFF

- Symptoms of PD such as slowness, stiffness or tremors are significant upon arising. This may be amplified by delayed-ON with the first dose of CD-LD.
- Strategies
 - Take a dose of CD-LD at bedtime or even better take a dose in the middle of the night if you wake up for the bathroom. This way your tank won't be empty when you arise in the morning.
 - If that doesn't work, let your provider know. There are specific remedies that can be prescribed to treat early morning OFF

Sudden OFF

- Symptoms of PD such as slowness, stiffness or tremors occur without any relation to when and how much carbidopa-levodopa is taken.
- Strategies
 - Keep track of when and how often the sudden OFF occurs.
 - Let the provider know about the sudden OFF. There are some rescue medications or on-demand therapies that can be prescribed.



TAKE CHARGE!

EDUCATE. SUPPORT. EMPOWER.

ALTERNATIVES TO CARBIDOPA-LEVODOPA

- Younger patients may be prescribed a dopamine agonist. These drugs mimic the activity of dopamine, are less potent than CD-LD, and have less risk of causing dyskinesia.
- Examples
 - Ropinirole
 - Pramipexole
 - Rotigotine patch
 - Apomorphine
 - Apokyn injectable
 - Kynmobi sublingual film
- These medications do NOT require individual adjustments as described for carbidopa-levodopa.
 - Notify the provider if the alternative medications are not effective.

SIDE EFFECT MANAGEMENT

Nausea

- Nausea may occur when carbidopa-levodopa is newly started or when increased.
- Strategies
 - Take CD-LD with food. Some crackers or half a banana is usually enough to block the nausea
 - Reduce the carbidopa-levodopa to the last tolerated dose.
 - Take Zofran 4mg tablet three times a day as needed.
 - DO NOT take Zofran if taking Apokyn or Kynmobi
 - Once the nausea has resolved, continue taking the Zofran while increasing the dose of carbidopa-levodopa.
 - Slowly stop the Zofran.

Increased Movement

- Determine if the increased movement is rhythmic like a tremor.
 - See strategy above for Delayed ON and Wearing OFF
- Determine if the increased movement is random, writhing and wriggling (dyskinesia).
 - Determine when the dyskinesia is occurring using the PD diary below.
 - If the dyskinesia is occurring when the carbidopa-levodopa is peaking then reduce that dose by ½ to 1 tablet.
 - If dyskinesia is occurring at the end of a dose period, then shorten the time between doses similar to Delayed ON and Wearing OFF.

Dizziness

- Read the website document Orthostatic Hypotension for more information.

Confusion/Hallucinations

- Consider orthostatic hypotension
 - Read the website document Orthostatic Hypotension for more information.
- If orthostatic blood pressure is not the cause, evaluate medication administration to verify that the correct doses are being taken at the correct time.
- Consider whether any new prescribed or over-the-counter medications have been added that may be causing the problem.
- If none of the above can be identified, then contact the provider to determine next steps. Lab tests to look for a urinary tract or other infection, electrolyte imbalance, and kidney or liver malfunction will be ordered by the provider.