

Moderator Joy

Good evening and welcome to this live "Ask the Expert" fully moderated chat. The topic of tonight's event is "Off-time Management in Parkinson's disease (PD)."

Moderator Joy

During this chat we will explore the definition of "off-time," talk about "wearing off," and describe how people with PD might describe their complex symptoms to their physician. We will also talk about the various approaches to treatment for "off-time" management.

Moderator Joy

This evening's live chat event is funded through an educational grant by Bertek Pharmaceuticals.

Moderator Joy

WE MOVE is a not-for-profit organization dedicated to increasing awareness of movement disorders and providing lay and professional audiences with balanced, timely, and accurate information on these complex neurological disorders.

Moderator Joy

Tonight's expert is **Dr. Mark Stacy**, a leading authority on the management of PD. Dr. Stacy is an Associate Professor and Director of the Movement Disorders Center at Duke University Medical Center in North Carolina. Good evening Dr. Stacy!

Dr. Mark Stacy

Hello! It's certainly good to be here.

Moderator Joy

The ground rules for tonight's moderated chat event are simple. If you have a question for Dr. Stacy, please type it into the message box at the bottom of your chat screen and then hit enter to send your question to the Moderators. They will pass your question along to Dr. Stacy. The question may then appear in the main chat window, followed by the answer from Dr. Stacy.

Moderator Joy

If you wish to say hi to a friend in the room, do not use the message box at the bottom of your screen. That is for your question to Dr. Stacy. Use the IM feature to talk to others in the room.

Moderator Joy

Also, many people submitted questions in advance of the chat via our Off-time Management Discussion Forum. So you may see pre-registered questions posted by our Moderator's and then answered by our expert.

Moderator Joy

We will do our best to answer all questions; however, it is possible that we will not have time to answer all the questions. If this happens, please go to the Off-time Management in PD Ask the Expert Discussion Forum at www.wemove.org.

Moderator Joy

We have a lot of ground to cover this evening so let's start off with a few basic questions (which WE MOVE received before the chat began) about "off-time" and its management. Then we will open the floor for your questions!

Moderator Richard

Preregistered Question: What exactly is "off-time" and what happens during "off-time"?

Dr. Mark Stacy

"Off-time" is the time during which anti-Parkinson medications are not working and PD symptoms are more prominent.

Dr. Mark Stacy

An international group of parkinsonologists (doctors who specialize in the treatment of PD) recently met to discuss this very question. We defined "wearing off" as: "A generally predictable recurrence of motor or non-motor symptoms that precedes a scheduled dose and usually improves with antiparkinsonian medication."

Dr. Mark Stacy

In a "cycle" of medication dosing, the medicine starts to work, and you start to have improved mobility, less tremor, and toward the end of the dosing interval--hopefully just before your next dose of PD medication dosing--the medicine effect declines--or wears off.

Moderator Richard

Preregistered question: What medication options are available for the management of "off-time"?

Dr. Mark Stacy

Management of off time is based on two strategies. The first is prevention -- keeping off time away by dosing with medications frequently enough to avoid it. And, management of off-time is highly dependent on your current drug regimen.

Dr. Mark Stacy

): If you are on one agent, such as carbidopa/levodopa (Sinemet), off time can be treated by adding a dopamine agonist (pramipexole or ropinirole) or a COMT inhibitor (entacapone or tolcapone). If you are already on 2 or 3 of these drugs, dosing schedules may be manipulated to prevent the down times. If this cannot be done, starting a rescue agent, such as apomorphine,

or perhaps a rapidly dissolving form of carbidopa/levodopa (Parcopa), may be needed.

Dr. Mark Stacy

Up to a point, levodopa can be taken more and more frequently, to maintain the overlap of effect from each dose. Other PD medications can also be added, such as a dopamine agonist in pill form, or a COMT inhibitor (entacapone or tolcapone).

Dr. Mark Stacy

Sometimes even adding selegiline or a new agent rasagaline may be helpful. Also, deep brain stimulation (DBS) is a surgical option when off time becomes disabling.

Dr. Mark Stacy

The second strategy for management of "off-time" is rescue therapy. This can be done with an injectable form of a dopamine agonist -- apomorphine (Apokyn) -- or by taking a rapidly acting levodopa formulation, such as liquid Sinemet (a dissolved tablet) or a new "melt-in-your-mouth" type of levodopa -- Parcopa. Both Apokyn and Parcopa were approved by the FDA for use in the United States this year. Apokyn reverses an off in as little as 10 minutes.

Moderator Richard

Preregistered question: When does "off-time" begin to occur in the course of PD progression?

Dr. Mark Stacy

In early PD, a person taking medications may not even notice when a dose begins to wear off. As the disease progresses, symptoms may begin to return earlier than expected. This is called wearing off.

Moderator Joy

What causes "wearing off"?

Dr. Mark Stacy

Wearing off happens because the cells that die in PD both store and release a chemical called dopamine. Levodopa, when take in pill form, is converted in the brain to dopamine. Dopamine agonists mimic the effect of natural dopamine in the brain.

Moderator Richard

Preregistered question: How can I best describe what I'm feeling during "off-time" to my doctor?

Dr. Mark Stacy

I think most neurologists and many general physicians are aware of the concept of off time. However, a physician may not always notice off time or wearing off during an office visit. This is commonly because, as a PD patient,

you will time your medication to be at your best during physician visits. If this is the case, you can choose not to take your meds, and let the doctor see first hand how your PD symptoms are at their worst, or simply inform us that you wake up and it takes 30 minutes for your meds to kick in, then they quit working 30 minutes before each of your next dosages. Then ask, "Can we change this dosing schedule or add another agent to keep it from happening?"

Moderator Cate

Please remember that the information you read here today is not a substitute for professional medical advice. The diagnosis and treatment of Parkinson's disease can only be reached after consultation with your own physician or other qualified healthcare provider.

punkycj1

QUESTION: I am taking my meds on time everyday, (just out of hospital) but I am falling more and more. I am 46 and was diagnosed 3 years ago, but have had PD for about 8 years.

Dr. Mark Stacy

Falling is a difficult issue to sort out online. It may be highly dependent on your reason for hospitalization. However, it sounds to me that you may be under treated for your PD. You might consider talking to your doctor about this. If your doctor believes your falls are caused by PD, this should take care of it. Another thing that I look for in PD is dizziness and check blood pressure sitting and standing. If you are falling from loss of balance, it could be that your PD medications are lowering your BP.

RIBLUE

I have a question. Do people with PD have muscle and joint pain, and what to do about it?

Dr. Mark Stacy

About 30% of PD patients experience pain. If your pain happens at the end of your dose, I would perhaps take it more often or add another agent.

Dr. Mark Stacy

Cont'd: If you have pain all the time, you may consider consulting a pain specialist and consult your general physician.

smiley

Dr. Stacy. Have you ever heard of Requip affecting hormones?

Dr. Mark Stacy

No, I haven't heard of any PD medication affecting hormones.

Moderator Richard

Pre-registered question: Does "off-time" ever stabilize or will it keep getting worse?

Dr. Mark Stacy

"Off-time" can be managed, and in that regard it can usually be "stabilized." But this requires good communication between you and your physician. Your physician should be able to stabilize you with levodopa and perhaps a dopamine agonist. If this doesn't control your off-times, there are new medications available including the subcutaneous apomorphine injectable, Apokyn, which can rescue you from an off episode quickly.

Moderator Richard

Pre-registered question: My off times are so unpredictable. Is there a way to treat them, even though I never know when they will happen?

Dr. Mark Stacy

Some people with PD know when an off time is coming. But, off times can also be totally unpredictable and that can be extremely frustrating. Perhaps the best way to arrest an unexpected off time is to use a rescue therapy, for instance, apomorphine injectable (Apokyn).

Moderator Cate

This is a fully moderated chat, meaning that your questions will not appear on the main screen. Moderators can see all of the questions and are sending them to Dr. Stacy for a response. It will help if you begin your question with the word QUESTION so that the Moderator's can quickly identify your question as it appears on their screen.

young

question/ Dr Stacy. My neurologist just upped my Requip by one pill a day and I was wondering if it could already be causing stomach problems. this was Monday it was upped.

Dr. Mark Stacy

All PD medications can cause nausea. So, if your nausea has increased since your Requip was increased, I would say that's the culprit.

punkycj1

QUESTION: The depression is very bad for me. They have me on all types of meds, but the depression is still there.

Dr. Mark Stacy

I think it's great that you have acknowledged the depression and talked to your doctor about it. That's half the battle! I try to obtain motor control for PD in hopes that this will also improve some of the symptoms of depression. If that doesn't work, I try a variety of SSRIs such as Zoloft, Paxil, Lexapro, Celexa, and a host of others. I will also try tricyclics such as Pamelor, Elavil, and a similar agent, Wellbutrin.

Moderator Richard

Pre-registered question: Can Apokyn be utilized to delay the need for DBS surgery?

Dr. Mark Stacy

YES. As one pioneering doctor in the world of PD research put it: "An APO a day, keeps the surgeon away." While this is a simplification of this issue, there are some patients not suited for DBS surgery. Apokyn is an ideal solution for this type of patient.

jule

I can't tolerate anything but Sinemet. Now I have been splitting my Sinemet in half and taking same amount just more frequently. Continuous seems a little better. Is this okay to do?

Dr. Mark Stacy

Before we had drugs beside Sinemet, we used to call this fractionating. If you cannot tolerate other agents because of nausea, please ask your neurologist if you can be provided with domperidone by writing you a prescription to send to Canada. The last time I checked, our President will still allow us to obtain this drug from Canada!

nsdeg

What is Apokyn?

Dr. Mark Stacy

APOKYN is a new, injectable, anti-Parkinson therapy. It is a dopamine agonist like Mirapex and Requip, but you inject it much like you would a migraine drug. APOKYN results in an arrest of PD symptoms within 5-10 minutes, with a duration for 60 minutes. This is called a rescue therapy. This drug is ideal for rescuing you from an off episode until your oral medications kick in 30 minutes later.

Moderator Richard

Pre-registered question: I have heard about Apokyn and heard that it is injected. Is that right? How do learn to inject?

Dr. Mark Stacy

Apokyn is indeed an injected medication. It is recommended that the first injection be done in your physician's office. At that time, instructions for dosing and injection will be provided. Although you may say I am on the "good end" of the needle, most people say the pain of the injection is not even as bad as a blood draw. Also, the injection is done with an "injection pen" and does not require a lot of manipulation.

nsdeg

My off time is characterized by freezing and festination. Recognize my "on time" when the dyskinesia kicks in. Is this usual?

Dr. Mark Stacy

Yes. The goal of your communication with your neurologist is to avoid the "trough" when you have off symptoms and avoid the "peaks" when you experience dyskinesias. This can be done by balancing levodopa and a dopamine agonist. After maximizing benefit with these two agents, I add amantadine. If these 3 cannot control your fluctuations, I will use levodopa, a dopamine agonist, and supplement it with apomorphine (APOKYN) for the "bad times."

punkycj1

QUESTION: Is migraines part of PD?

Dr. Mark Stacy

No, migraines are not considered a part of PD.

trickey

What qualifies us for this new drug?

Dr. Mark Stacy

I would prescribe this drug for unpredictable "off" periods and inconvenient "off" periods. There is no real qualifying symptom; however, many insurance companies may not be covering the agent.

Moderator Richard

Pre-registered Question: Are "on" "off" phenomena found primarily in those taking levodopa or Sinemet? I have been on mono therapy (agonist) for 5 years, have never taken Sinemet, and do not experience on-offs in a pronounced way. Yet I experience sleep disturbances, depression, apathy, and am easily distracted.

Dr. Mark Stacy

These situations are common PD experiences. I would consider trying or changing to another medicine for depression in this case.

Moderator Cate

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young

Question. Can stress effect when off times occurs?

Dr. Mark Stacy

Stress may magnify the duration and extent of "off" time and may also magnify dyskinesia. It is important to recognize stress as an "amplifier" of these systems because if the stress is treated with PD agents, it won't improve. Significant anxiety should be treated with an anti-anxiety agent or an SSRI.

Moderator Joy

Preregistered Question: I often find myself off 30-45 minutes after taking levodopa. Should I take more immediately, or is the last dose I took about to kick in? I have had PD for 26 years.

Dr. Mark Stacy

Typically, in early PD, I dose Sinemet at 4-5 hour intervals. With time, 4 hour intervals are too long between dosing. If you are now getting only 3 hours of benefit for each dose of Sinemet, I would consider adding a COMT inhibitor (Comtan or Tasmar), or adding a dopamine agonist. At 26 years of PD, I hope you are taking both a dopamine agonist and Sinemet and have already tried Comtan. In your case, you might benefit from intermittent Apokyn injections for those inconvenient off-periods, but I would also consider deep brain stimulation (DBS), which may allow you a great deal more freedom and mobility.

RIBLUE

Dr. Stacy is taking Celebrex ok for pain.

Dr. Mark Stacy

Yes.

Guest

QUESTION: Is the percentage of DBS patients better than those without taking it? Are people who have had DBS for PD have a better time managing their disease?

Dr. Mark Stacy

That's a complicated question. In general, patients who I recommend to DBS can no longer be managed adequately with medications alone. So, if this is the case, they will be better off with the DBS and an adjustment of their medications.

Moderator Richard

Pre-registered Question: Hi, I was diagnosed with PD a little over 10 years ago. My doctor tells me I am at the point where I am taking as much medicine as I can take. So, I am experiencing more and more off time. Right now I am waiting for 2 new medicines to come on the market; they are rasagaline and the Rotigotine Patch. Right now I take Requip, 5mg, 3 times a day and Sinemet, 25/250, quartered 4 times a day. I don't know what I am going to do until something new comes available. Do you know of anything I can do now?

Dr. Mark Stacy

There are probably more reasons to your doctor's statement of maximum medication that are mentioned here, but the maximum dosage of Requip (ropinirole) is 24 mg/d, and I would suggest that you change to Sinemet 25/100 1/2 to one tablet every 3 hours. This would change the effective dosage from a quarter of a 25/250 (or a 6.25/62.5 mg dose) to a 12.5/50 or 25/100 mg dosage. At the very least you do not have to quarter a tablet. I would also consider taking Comtan to make Sinemet last longer, and perhaps add Amantadine if you are having dyskinesias. Have you tried Apokyn injectable to manage your off-time?

NOW the confusing part! Rasagaline is a drug similar to selegiline - so you might start that drug before rasagaline is available 2nd quarter 05. Also, rotigotine patch is a dopamine agonist, and has similar efficacy to Requip. If these issues have already been addressed, there are a number of drugs in clinical trial that may help this problem. They include Sarazotan, Istradefyline, and others. Ask your doctor or look at WE MOVE for current information.

One thing to remember if you decide to participate in a clinical trial is that the participating institutional doctors may want to try available medicines before enrolling you in a specific trial - so don't get your heart set on being a guinea pig.

Jamie

How many people are misdiagnosed? If someone has been misdiagnosed, how harmful are Sinemet and Mirapex to your system?

Dr. Mark Stacy

There are no data to suggest that levodopa or dopamine agonists cause harm to people who do not have PD.

Moderator Richard

Pre-registered Questions: How long does it take for medicines to work?

Dr. Mark Stacy

The time for medicine to "kick in" varies from dose to dose, patient to patient, and by drug. In general, a "kick in" is usually not felt with a pill or patch form of a dopamine agonist. Apokyn will kick in the fastest - usually 10 to 15 minutes. Carbidopa/levodopa (Sinemet) will kick in at 20 to 30 minutes and Parcopa, a rapidly dissolving carbidopa/levodopa tablet, may be faster.

judy ruth

Does the use of Serequel help depression?

Dr. Mark Stacy

Seroquel is not an antidepressant, per se. However, it is a drug that helps sleep and hallucinations. So if depression is aggravated by sleep deprivation, the Seroquel will help.

Moderator Joy

Pre-registered Question: I am having trouble sleeping at night. What can I do?

Dr. Mark Stacy

There are a lot of issues with sleep in PD. Perhaps the most common is too much sleeping during the day. If you have excessive daytime sleepiness, increase your daytime activity, especially at those times you usually nap, exercise, and a little caffeine with meals never hurts.

If it is insomnia, determine if it is difficulty falling asleep or difficulty staying asleep; most of the time in PD it is staying asleep. Try this regimen: 1) Go to bed at the same time every night for one month. 2) Start your day at the same time every morning for three months (This will reset your circadian clock). 3) If you need help to get to sleep, try Tylenol PM, no more than directed. 4) If this does not work, discuss sleeping agents with your doctor.

Another issue in sleep in PD is a condition called REM-behavior disorder. This is a condition of excessive or acted out dreaming with sleep. This often is more bothersome to the bed partner than the patient, but often responds to clonazepam 0.5 - 1.0 mg at bedtime.

trickey

I am newly diagnosed 2 yrs now and I am recently experience major fatigue. Is this part of PD?

Dr. Mark Stacy

Fatigue in early PD is likely related to your medications. In general, dopamine agonists like Mirapex and Requip, may be linked to sleepiness. All PD medications may cause low blood pressure, which can make you tired. Are you dizzy in the early morning or sleepy after a large meal? These can be clues.

I still use my favorite drug for treating my own fatigue...that would be caffeine! And I think, if you have PD, you might want to consider a cup of coffee at breakfast and lunch.

Moderator Cate

You may have noticed that when you typed your message into the lower window, it didn't appear in the top window. This is because we are using a format known as a moderated chat. The Moderator's can see everything that you are typing, and we are selecting questions for Dr. Stacy to answer, but other people in the room can only see the questions that have been answered by Dr. Stacy.

RIBLUE

Dr. When you do a lot in a day, do u need your meds early? I also have depression. I take Zoloft during the day, and another pill before bed time. Sometimes worry I take too much. I was on 200 Zoloft but cut down to 100. I have had lots of stress and it got worse (death in family)

Dr. Mark Stacy

I'm very sorry about your loss and your stress. Perhaps 200mg at this time is reasonable, with reduction after this acute stress diminishes. For someone who experiences depression at the end of the day, I might suggest they add a dose. Of course, you must clear this with your physician.

Chas

Question: I was diagnosed w/ PD in '98 and am taking Sinemet CR 25/100 X 4 daily, Amantadine 100 X 2 daily, and my Dr. added Requip one year ago. I am now taking 3mg X 4 daily. My ? is that I have never had "off time versus on time." How common is this?

Dr. Mark Stacy

My first reaction to your question is that I agree with your medications. You are on a reasonable therapy for someone with PD for six years. However, are you saying that you don't have a benefit from your medications? If so, you should discuss this with your physician and he/she may consider a gradual withdrawal of PD medications.

If your symptoms return after the withdrawal, then you were being well managed on those doses.

Moderator Joy

Pre-registered question: Are disturbances of your mental health or ability linked to the on-offs of Sinemet?

Dr. Mark Stacy

It seems that depression and decreased cognition are separate from the "movement disorders" (tremor, rigidity, balance, etc.) that are the "traditional" PD symptoms that Sinemet corrects. There is increasing emphasis on non-motor symptoms of PD.

SisDailey

Dr. Stacy. What about stem cell research?

Dr. Mark Stacy

Stem cell research has certainly received a lot of press in the last few weeks. It holds great but unknown promise for many diseases. I believe the hope is important and I hope that we will be able to explore these therapies in the future. At this time, I do not know of any stem cell work being done with

dopamine-producing stem cells. And I don't know of any work being done in the world with stem cell implantation for PD.

supmrio

ques: PROVIGIL - is this ok for stay awake during the day?

Dr. Mark Stacy

Provigil is an excellent drug for fatigue in PD and daytime sleepiness but it is sometimes unpredictable in terms of benefit. My suggestion is to try Provigil for a short time to see if you notice a response, but to not wait for more than a month if you don't see a response.

mje

Question: I am 49 years old and had PD 13 yrs, had DBS surgery 6/04 and am only taking Sinemet and Comtan. Should I be taking an agonist also?

Dr. Mark Stacy

If you require additional anti-PD therapies, then a dopamine agonist would be the first drug I would add.

Moderator Richard

Pre-registered Question: I have a question. I take Requip 3x a day 1mg. Can an extra dose be used to help me with toe cramps?? I also take Artane, 2mg 2 x a day and amantadine 2 x day 100 mg.

Dr. Mark Stacy

Absolutely. In fact most dosing studies of Requip suggest 6mg per day as a minimum dose. I would suggest asking your physician if he or she advises that you increase your Requip dose. This may allow you to stop your Artane.

Moderator Richard

Pre-registered Question: I am a Parkinson patient of 6 months and have experienced immobility, not speaking, arms and hands froze next to the chest. I take Sinemet (25/100-2 tab. every 8 hrs.), Comtan, and Mirapex. Sometimes I have hallucinations.

Dr. Mark Stacy

You appear to be taking a lot of medication so early in the course of PD. I would suggest discussing a dosing change to: Sinemet 1.5 tablets at mealtimes and 1 tablet at bedtime. Take one Comtan with each daytime dosage.

Mirapex should be dosed at 1 mg three times a day (meals!), but this is the one most likely to cause hallucinations. Perhaps you should discuss decreasing this agent, or even stopping the drug. If this cannot be done, quetiapine 25-50 mg at bedtime may stop the hallucinations.

nsdeg

I am 11 years with PD but have never had tremor. My dyskinesia and freezing are severe. Am I a candidate for DBS?

Dr. Mark Stacy

I believe you are a candidate for DBS. I do not look at tremor as a yes or no to surgery. My biggest concern is do you get dyskinesias and do you respond to PD medications. Then hopefully DBS will help your freezing AND your dyskinesias.

Moderator Cate

Please feel free to chat with other people in the room using the IM feature. To do so, simply click the "user" tab on the right-hand side of your screen and double click on the name of the person (XXX) with whom you would like to chat. A new window will pop up that is called "Private Conversation with XXX." Simply type your message to that person in this new window.

Moderator Richard

Pre-registered Question: I don't shake. When my drugs work I can stride with arms swinging. It's easier to type with both hands. I can hit a golf ball! It's easier (emotionally) to handle hurricanes! Can't sit still. Gotta get stuff done. Unfortunately, I don't get this "on" time with every pill. Nor do I necessarily get it every day. I've been told that there's no pain with PD. UNTRUE! Off time for me includes: pain and stiffness on my right side (to a lesser degree on my left side), debilitating toe cramping of my left foot, urinary urgency (in the middle. LOL. Gotta have a sense of humor!), exaggerated emotions, loss of vocabulary, loss of ambition (sitting in a rocking chair watching the Tube is good!). Of the PWP I've met, I'm the only one with these symptoms. Am I alone?

Dr. Mark Stacy

Approximately 30% of patients with PD will report pain, so maybe others in your world have not been paying attention. Usually the pain is exactly as you describe, foot cramping with wearing off. Your non-motor PD symptoms are also typical, and in your case a rescue of these symptoms with Apokyn may be a perfect solution. Before that I would suggest optimizing your medication with a combination of carbidopa/levodopa, dopamine agonist, and a COMT inhibitor may reduce the winds of your motor fluctuations from hurricane force to at least tropical storm.

trickey

I recently had an MRI and it showed spinal stenosis. Is this part of PD. I see my neurologist on Dec 6th to discuss this but I thought I'd ask while you were online

Dr. Mark Stacy

Spinal stenosis is not part of PD but can aggravate walking problems. Typically, a spinal stenosis walking pattern is bent forward at the waist about 15-30 degrees. And, in people with PD and spinal stenosis, I try to optimize

PD treatment first. But, if upper extremity movement improves but not lower, then I assume the spinal stenosis is playing a big role.

Moderator Richard

Pre-registered Question: I believe that I have become psychologically addicted to Sinemet. I have very volatile reaction to the hour or so period where the drug is wearing off. However, I go twice as long without it while sleeping. How can I soften the effects of the "wearing off period?"

Dr. Mark Stacy

You might discuss adding a COMT inhibitor or dopamine agonist with your doctor.

supmrio

question: How can one best maximize Tasmar?

Dr. Mark Stacy

Tasmar is a drug that typically lasts 6-8 hours so you can use 100-200 mg 3x per day.

Moderator Richard

Pre-registered Question: I find in the off time I have a great deal of pain from my osteoarthritis of the spine. Do you know how to help this?

Dr. Mark Stacy

I believe your off-time pain is from muscle rigidity in the back. I might suggest that flexibility exercises with a physical therapist and shortening your medication dosing intervals to lessen off-time phenomenon. If this doesn't work, you may want to consider rescue therapy with Apokyn.

Moderator Cate

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Moderator Richard

Pre-registered Question: I want to help my father in physical therapy including speech but don't know how!

Dr. Mark Stacy

The National Parkinson Foundation (NPF) has a great booklet addressing speech problems in PD.

Jamie

Question: How does alcohol affect PD meds? Is it okay to have a glass of wine or two in the evening?

Dr. Mark Stacy

Alcohol will not directly affect your medications but may slow the rate at which they are absorbed from your intestinal tract. I would not object to one glass of wine with dinner, but if one-two turns into three to four, then I would advise against it.

Moderator Joy

The Moderators are ready to receive your questions.

Harriet

I am afraid of shots. Can I still use Apokyn?

Dr. Mark Stacy

People who are afraid of needles are VERY common. Currently we ask patients to come into the office and are given their first shot by a nurse who is trained to give the shot AND help you relax. It is my belief that, if you have a great benefit from APOKYN, this will lessen your fear of the next shot.

Moderator Richard

Pre-registered Question: Isn't there some nausea associated with Apokyn? Does it require another drug to manage that?

Dr. Mark Stacy

Excellent question about the nausea. Apomorphine was originally used in emergency rooms to induce vomiting in children who have ingested a poison. Apomorphine was also the first medicine ever used to treat PD. In PD, apomorphine seems to produce less nausea, but all patients will require an anti-emetic, which is a drug that helps to lessen nausea, before beginning Apokyn therapy.

However, it has been our experience that over time, the anti-nausea drug may be withdrawn. In the US, Tigan 200mg, 3x a day is initiated 2 days before beginning Apokyn. In countries where domperidone is available (not in the US), that is the anti-emetic of choice. I will remind everyone that many PD drugs can produce nausea but it is fair to say that apomorphine is the most likely.

RIBLUE

What about foot pain and toes curling?

Dr. Mark Stacy

This is a very common PD symptom and typically occurs in the early morning, 6-8 hours after the last medication dose. It usually responds readily to anti-PD medications. If it does not, you may consider asking your doctor to prescribe baclofen at bedtime and with your first morning PD medication dose.

Marg M

Is Botox ever used to break an extreme muscle spasm that gets a lot worse with off-times (shoulder)?

Dr. Mark Stacy

I would not use BOTOX to treat cramping pain. I would consider using Apokyn if the pain was associated with wearing-off from PD medications. This will relieve the cramping pain within minutes and would advise you to also take your other medications then too.

Harriet

What PD drugs affect thinking?

Dr. Mark Stacy

PD medications, if given in high enough dosages, can mimic symptoms of schizophrenia. I suppose in that regard, they can negatively affect thinking.

Jamie

Question: Why is it that some people with PD progress more quickly with symptoms and others can go years using meds and keep symptoms at bay?

Dr. Mark Stacy

I truly do not know the answer to your question.

Bart

Sometimes the on-off transition is gradual, sometimes almost a surprise. Mostly expressed by feet freezing. Is there a way to keep it smooth?

Dr. Mark Stacy

It sounds like you've made every effort to "keep it smooth." But sudden offs can be very frustrating and only respond to rescue therapy, such as Apokyn.

supmrio

Ques: Can you briefly describe Sinemet's journey to the brain, and what happens when protein enters the picture. I don't seem to be able to surmount this problem.

Dr. Mark Stacy

Levodopa is an amino acid that is absorbed from the gut to the blood stream and then from the blood stream to the brain by a large neutral amino acid carrier.

In some patients, eating protein that contains other amino acids that are absorbed using this same carrier, will reduce the effectiveness of levodopa. In my experience, this occurs less than 5% of the time and my blanket advice is to eat. A corollary however is if you eat a hamburger and your mobility suffers, then you should probably be careful with protein intake.

Moderator Cate

Please remember that the information you read here today is not a substitute for professional medical advice. The diagnosis and treatment of Parkinson's disease can only be reached after consultation with your own physician or other qualified healthcare provider.

Jamie

Question: My kids are scared to death they are going to develop PD. What is the current thinking of physicians in regards to PD being hereditary?

Dr. Mark Stacy

There are some PD syndromes that are linked to families. This however is NOT typical. If there is no one else in your family (parent, sibling) {with PD}, then the potential for your children to be at risk for developing your PD is probably remote.

Moderator Richard

Pre-registered question: Is it OFF time when I sweat and have internal shakes?

Dr. Mark Stacy

Yes, most likely.

Birds Eye 5

Can you tell be about Parcopa?

Dr. Mark Stacy

Parcopa is a newly approved carbidopa/levodopa agent that does not require water to swallow. It would be terrific if it were absorbed more quickly than traditional carbidopa/levodopa, but data does not support this. However people who have difficulty swallowing pills might find this an ideal addition to their regimen.

Moderator Joy

Time flies during chats! Doesn't it? A special thank you to each and every one of you for participating in the WE MOVE Off-time Management in PD chat event, funded through an educational grant by Bertek Pharmaceuticals.

Moderator Joy

And how about a big round of applause for Dr. Stacy!

Moderator Joy

Clap, clap, clap, clap, clap, clap, clap, clap, clap, clap, clap.

Moderator Joy

We hope that you found this chat to be helpful as well as informative. Be sure to revisit the WE MOVE chat rooms. Remember that the comments and postings in the WE MOVE chat rooms are not derived from WE MOVE-

approved educational content and therefore, have not undergone WE MOVE's medical review.

RIBLUE

I would like to thank you all for this chat. It is very nice of you Dr. Stacy and everyone else THANKS

Dr. Mark Stacy

Go Cardinals!! Good night everyone and be well!!

Moderator Joy

The information obtained during WE MOVE chat sessions does not replace consultation with a physician. All medical information, procedures, drug doses, indications, and contraindications should be discussed with your personal physician. So, if you have additional questions specific to your case, please discuss with your diagnosing physician.

A transcript of this chat will be available on Friday, October 29th. Please go to the WE MOVE home page at www.wemove.org to access the link to the transcript.

The content of this chat will also be summarized into a set of downloadable and printable FAQs (Frequently Asked Questions) on "Off-time Management in PD." The first of these FAQs will be available at the WE MOVE web site in November.

Moderator Joy

Again. Thanks for your participation.

RIBLUE

clap clap clap

Joe McIntyre

Thanks. Very helpful!

SisDailey

Thanks Dr Stacy

Jamie

Thank you Dr Stacy

RIBLUE

Go Boston

Chas

Goodnight and thank you for presenting this chat. It is very helpful to me and my family.

supmrio

For he is a jolly good fellow

RIBLUE

CLAP CLAP

HONEYPOT

Thank you

mj

It was a wonderful experience.

Jamie

Hope we can do it again Dr.!

mj

I'm glad I could join in even though I didn't ask a question.

smiley

Thank you very interesting

judy ruth

Thank you everyone. This has been very enlightening and i look forward to the next session

RIBLUE

This was nice

HONEYPOT

Be back in a few

Guest

Night all

smiley

What will the next topic be?

Moderator Joy

Good night again everyone.

smiley

Caretakers

Moderator Joy

That would be a great topic. Thanks

SisDailey

Nite Joy and thanks

Sander

That was really great.

smiley

Yes. Crabby sue you missed a lot.

CrabbySue

Lots of new faces here tonight

CrabbySue

Sorry i missed it. guess I'll wait til the transcript comes out.

CrabbySue

Seems it was most successful.