

**The Victory Summit® event:  
Medication and Parkinson's**

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Davis Phinney Foundation

Melani Dizon (Director of Education and Research, Davis Phinney Foundation):

Just a little bit about Dr. Haug and his bio, but you can see the full spread in our program book or online. And also, you'll learn a little bit more about him as he's talking for sure. So, Dr. Haug is a neurologist and movement disorder specialist practicing in Denver at Blue Sky Neurology. He's interested in medical and surgical treatments for the motor and non-motor symptoms of Parkinson's. He's involved in patient education through a variety of advocacy groups, including the Parkinson's Association of the Rockies. Outside of the office he likes to spend time with his family playing ultimate frisbee and follows the Kansas Jayhawks basketball and Colorado Rockies. All right, I'm going to let you take it away.

Dr. Aaron Haug, MD (Movement Disorder Specialist, Blue Sky Neurology):

All right. Thank you very much Mel. It looks like my slides are showing. Okay. So, I think we're good to go. I'm honored to be here with the Davis Phinney Foundation. I love these venues where we're able to talk about some basic as well as advanced concepts related to the treatment of Parkinson's. And what I'll be talking about in this "Newly Diagnosed Victory Summit" today is some of the basics of the medical management of the motor symptoms of Parkinson's and talk about what that means. So, I'll be using a little bit different format than Dr K, which was a great conversational discussion of many topics. And I found that myself to be very helpful. So, like Dr. K I am a movement disorder specialist. So, let's talk about some medical treatment of motor symptoms in Parkinson's.

So, when we talk about the motor symptoms in Parkinson's, we're talking about a subset of some of the symptoms that can occur in Parkinson's and they are often the most obvious ones that often lead to the clinical diagnosis of Parkinson's. And so, these are usually tremor, stiffness, and slowness. So, tremor usually occurs at rest, only occurs actually in about two thirds of people with Parkinson's. So, the lack of a tremor is not an exclusion of the diagnosis of Parkinson's. About two thirds of people do have some tremor. Stiffness, the medical term that we use for that is rigidity, and this often manifests when walking as a decrease in the arms swing, or sometimes the arm even being held in a flex position and then slowness, or the medical terms that we use our bradykinesia for slow movement or akinesia for lack of movement. So, as we go through this webinar, we'll be talking about some strategies of medical treatment, as well as some specific medications that might be used in recently diagnosed Parkinson's.

As we go through this, I think it's important to know that not everyone will have all symptoms. Parkinson's is a highly variable condition and what may be one person's most bothersome symptom, may be something that another person doesn't have to deal with at all. So, this is not a checklist as we go through this lecture or all of today's events of things that you need to be watching for or worrying about, but rather if these are things that arise, then know that we have tools in the toolbox for how to address them. So, speaking of baseball, the late great Yogi Berra that may have said that "it's tough to make predictions, especially about the future." And that is kind of what I'm speaking to here is that we have tools that we can use, but not all of these tools are always necessary. And also because of the variability of Parkinson's, although I hope to provide useful information for you for your specific situation, do talk with your own medical provider.

So, I'll highlight some action steps to kind of bear in mind as we go through this webinar together today. So, the first step would be to discuss with your provider whether to start or increase or add a medication. I saw on the chat just a few minutes ago - somebody said that their main question after being diagnosed about a year ago is when to start - and that is a real struggle for a lot of people. And I'll touch on that.

I think another action step that is very helpful both for the person with Parkinson's and their care team, as well as their family is to create and update a medication list and keep it with you all the time. Due to the way that the medical system exists currently, your primary care office and your primary neurology office and your movement disorder specialist office may not have direct access to each other's systems. And even if they do, what you're actually taking, what you're actually putting in your mouth, you're the only one that knows that. And so, having an up-to-date medication list and having it with you at every doctor's appointment is very helpful, especially if you might end up on even more than one part Parkinson's medication over time.

Then all I'll have a little bit of an aside about a tool that's available called a good RX, which can be helpful when you're trying to understand the relative cost of some of these medications.

This is a slide with a lot of words on it. And these are basically all of the medications that are used to treat the motor symptoms of Parkinson's. So, there are these seven main categories of levodopa, the dopamine agonists, and other ones that are spelled out here. We will talk about some but not all of these, but as was mentioned earlier, there is a webinar that I did with the Davis Phinney Foundation last year, where I do talk about all these medications and that's easily, find-able on YouTube if you search for the Davis Phinney Foundation and my name. So, if this only whets your appetite, what we discuss here today, then there's more available for you. So, what I would like to talk about today are what are the meds that are most commonly used among people that

have been recently diagnosed? So, these are some of those same medications, but this is maybe a little bit easier to bite off. And so, we'll talk about each of these in turn, they'll levodopa, dopamine agonists, and then categories that are called MAOB inhibitors, COMT inhibitors, and amantadine.

So, there's so much information. And some people may have felt like this in the past or may still feel like this. Hopefully you'll feel a little bit less like this after a while, where everyone in this room is saying, all these people really seem to have it together and I still have no idea what's going on. So, my hope is to reduce some of this type of feeling if you're having it currently. So, as we go through these medications, let's use a theoretical case that may help to illuminate some of these points. So, we'll talk about a theoretical patient of Mr. Clay.

So, he's a 60-year-old man, and he has about six months of left sided resting tremor. He has also noticed some difficulty with his fine motor skills, like buttoning these little buttons on his collar or cufflinks and that sort of thing. And others have noticed something that he hasn't really noticed himself, which is that when he's walking, his left arm is like it's holding an invisible suitcase. It's not really swinging at all, unlike the other arm. And so, he goes to see a neurologist. And as many of you have discovered is the case, it is often a clinical diagnosis made based on what symptoms are having. And other non-motor symptoms that we may ask about like constipation, dream enactment behavior, your sense of smell. And so, Mr. Clay, based on his symptoms and his physical examination is diagnosed with Parkinson's. This leads to an avalanche of questions. One of which is, should I start medication? And this actually contains a number of related questions underneath it. What does medication help? How much does it help? What side effects might I have? How many times a day am I going to have to take this? What might the medication cost? And so, I'll help to sort these things.

So, the context is very important. No two people with Parkinson's are the same and no two people's situation is quite the same. So, the guiding light, when we're talking about the treatment of symptoms in Parkinson's is quality of life and optimizing enjoyment and function and doing what you want to do and what you need to do. And so, taking the context into consideration, we consider that Mr. Clay, he's working full-time, he's an engineer and he occasionally has to give presentations at work. And the tremor can be embarrassing, especially if he's holding a laser pointer, which really augments how visible the tremor is from across the room. On a day-to-day basis, he notices some soreness and stiffness in the arm, which seems to be from how much he's shaking and because of, overall, his movement difficulties, he's found that he used to exercise, but now he's not doing that as much because it's more difficult. So, this is the context that Mr. Clay is working with it. And so now circling back to the question of, should I start a medication? Based on his symptoms and his overall situation in life and how bothersome his symptoms are, I would recommend that he start medication.

Follow up questions to that. Well, shouldn't I wait until my symptoms are worse? I mean, I can put up with the tremor the way that it is now. And also, I've heard that medications only work for a few years. Am I using up my options if I start medication now? Regarding the question of shouldn't I wait? The answer is usually no. There's research that shows that postponing treatment mainly accomplishes decreasing your quality of life. Although you might think that you can save the medication for a rainy day. In fact, the effectiveness of the medication in the future is not going to be as great as it might be now because as Dr. K was saying, the nerve cells, the brain, continues to experience the progression of the disease, regardless of whether you're on medication or not. And so, if symptoms are impairing quality of life and function, we typically recommend starting treatment.

Well, what about I heard that medications only work for five years. This is kind of the same story from a slightly different angle. It is true that medications work best in the early years of having Parkinson's and working best in this case means fewer of the ups and downs, fewer of the motor fluctuations as we call them. And also, a lesser likelihood of dyskinesia when you've been on medications for fewer years. But this has as much to do with how many years you've had Parkinson's as it does with how many years you've been on medication. And what this means, unfortunately, is that if someone really tries to tough it out and they've been suffering from their tremor or other physical symptoms for several years, hoping that they can save the medication and get these five years so to speak, later, sometimes after they've been waiting and waiting, they start the medication, and because their underlying disease has continued to progress, they might run into some of these complications, the fluctuations, or the dyskinesia is not just five years after they've started the medication, but sometimes even within the first year or less of starting the medication, because the number of years that you've had Parkinson's is something that we can't control.

Okay, well if we're going to start medication what are my options, which medication should I consider? I think it's a fundamental truth of currently when we're treating Parkinson's that there are multiple reasonable places to start. And the preferred strategies vary among providers, as well as among people with Parkinson's.

Carbidopa/levodopa... I think Dr. K laid some excellent groundwork and talked a lot about the nuances of using carbidopa/levodopa. It is indeed the gold standard of treating the motor symptoms of Parkinson's. So, the levodopa, sometimes it's helpful to see these things in writing. Sometimes we call it L-DOPA for short, that is what is converted to dopamine in the brain, the levodopa is a precursor or a building block of dopamine. The carbidopa, it is just there as a transporter, basically to keep you from having the levodopa converted to dopamine in your stomach, where it makes you nauseous or flowing through your bloodstream, or it can make you faint or lightheaded. We want the carbidopa to prevent that, allowing the levodopa to get into the brain, into the nervous system where it can be turned into dopamine, where we need it. Levodopa is the most effective medicine and improving motor symptoms. So, whether that's

tremor or stiffness or slowness. For most people, levodopa is the medication with the most benefit. What are the possible common side effects? Well, the two most common are the ones that I just mentioned, that carbidopa is there to prevent, but it's not all always fully preventable. Nausea and lightheadedness are probably the two most common side effects, but it's important to note that really any of these medications that work to increase the amount of dopamine in your system, any of those medications can cause nausea and lightheadedness.

So, when we talk about carbidopa/levodopa, there's actually several options. And for our purposes today, I'll point out that generic carbidopa/levodopa is by far the most commonly used. The old brand name of carbidopa/levodopa, Sinemet<sup>®</sup>, we don't actually prescribe that brand name medication very often because it's more expensive and the generics accomplish the same thing, but you will often hear us say Sinemet, because carbidopa/levodopa is such a mouthful to say every time. And so, when we say Sinemet, we usually mean generic carbidopa/levodopa.

We'll talk a little bit more about, well, why might I pick that versus another, after I talk about what maybe the second category is here. So, the dopamine agonists. So, like the dopa, agonists provide benefit for the main core symptoms, the tremor stiffness and slowness, and it's the agonists are generally considered to be the second, most effective category of medication behind levodopa, but there are certain advantages and disadvantages that might point us towards picking one versus the other. So, what are some of the advantages of a dopamine agonist? Well, over the course of several years of taking medication, the agonists are less likely than levodopa to cause dyskinesia or fluctuations. The dopamine agonists also have a possible benefit for some of the non-motor symptoms like depression.

The disadvantages of dopamine agonists is that there can occasionally be other unpredictable side effects that we don't see as much with any of the other classes of medications. And some of that can be what we call excessive, daytime sleepiness, or even sleep attacks, falling in the middle of doing something like sleeping, eating, or talking, eating, or driving or like swelling can be more common with dopamine agonists than it is with other medications. And then important to notice is that although most dopamine medications will say in their information that they can potentially cause what are called impulse control disorders, it is more of a problem with the dopamine agonists. And so impulse control disorders, anything that normally human beings are drawn to like spending or gambling, sexual behavior, can potentially become more problematic and compulsive as a side effect of some of these medications, particularly the dopamine agonists.

So where do dopamine agonist fit in? Due to this lower risk of dyskinesias over the course of several years, they will sometimes be used as what's part of what's called a

levodopa sparing strategy. The options include pramipexole, Mirapex® was its branded name, or ropinirole, which is Requip®. And then there are some others as well, but these are the two most commonly used.

The third category among these three medications that might often be a first-line consideration would be the MAOB inhibitors. So, MAO is monoamine oxidase, this is an enzyme that we all have in our brain that's involved in the normal recycling of dopamine. And if you inhibit this enzyme, then that leads to more dopamine being in circulation in your system, in your brain. Generally, this category of medications is not quite as robust. It has more of a mild benefit for the tremor, stiffness and slowness, but they do tend to be well tolerated. The possible side effects with MAOB inhibitors are the same as with other medications, you'll see the possibility of nausea, the possibility of lightheadedness, but it's less likely with this category than it is with some of the other categories. So, this might be used often alone in early Parkinson's. If the motor symptoms are fairly mild or it might be used in combination with other medications in later stages of Parkinson's. And as I mentioned, because there are fewer side effects, this is a medication that can often be used in people who are older. I didn't mention on the previous slide about the dopamine agonists, but the sudden sleepiness or the leg swelling, those are more problematic in older populations. So, while I might be somewhat more likely to use a dopamine agonist in someone who's 50 or 60, if someone is 70, then I'm less likely to use that category of medication because of those possible side effects that can occur.

So, when we talk about, what are the options within the MAOB inhibitor category, the two most common that use the two most widely available are probably selegiline, which used to be called Eldepryl®, as its branded name or rasagiline, which had the old, branded name of Azilect®. So, we've talked about some of these three different categories that might be used as a first-line medication. What should we do for Mr. Clay? So, we talk about levodopa, the dopamine agonists and the MAOB inhibitors. And based on the fact that his symptoms are affecting his ability to work, we decided to start with the gold standard, the carbidopa/levodopa and a typical starting dose, you might right ramp up to this over a week or two twenty-five slash a hundred milligrams three times a day. So, let me have an aside here about well what is the cost of medication? This is something that honestly physicians are sometimes unaware of because what medications cost is a complicated formula, a complicated interaction between what's your insurance plan, what pharmacy are you using, what contract does that insurance company have with that pharmacy? It can be a real maze.

Some Parkinson's medications are inexpensive, and others are expensive. The cost may vary by insurance, by pharmacy. And so, there's this tool, a free tool called good RX that can be useful for comparison. And sometimes the good RX can actually be something that you use instead of your insurance and possibly get a lower cost than

you get with your insurance as strange as that may seem. So, this is a free service and there's no subscription required. Apparently, they make their money by the ads that are on the sidebar of their website. And this is available either online or through the good RX app that you can get on any smartphone. So, I'll just give you a brief example of how this might work.

So here I've pulled up [goodrx.com](http://goodrx.com) and across the search bar here, you can type in carbidopa/levodopa since that's what we're starting for Mr. Clay. And then here's a partial screen image of what you would see. So, carbidopa/levodopa, which is generic for either Parcopa® or Sinemet. And you look at a couple of the most inexpensive pharmacy options, City Market, or King Soopers. It says if you're doing 90 tablets, which would be a typical one-month supply, then, even if you had no insurance, but you use this good RX free discount card that you can get by clicking on that green button and either printing out or showing to the pharmacist on your phone, then a month prescription would be \$14. Now they may run your insurance and say, Oh, with your insurance, it'll be \$4. In which case, just go with that. The caveat is that if you use good RX to get this \$13.95 discounted price, then it's not using your insurance at all. And so, it's not counting towards your deductible. So, there's a lot of nuance that goes into navigating the healthcare system, unfortunately sometimes.

And so, if you click on that little green button, then it will show you something like this. And the pharmacist will say, okay, well, I ran your insurance...well, could you run this instead? And they would type in this code and this group and this bin number. And they would say, oh yeah, we can give you that 1395 price. Instead of, for some reason, your insurance was going to cost say \$20. So, the good RX could maybe save you some money in that example. Don't print out this one. This one this is just a sample. You would actually go to the website and enter the prescription number, specifics of what your prescriber has prescribed.

With our case, Mr. Clay starts the carbidopa/levodopa. And initially he does have some knowledge that maybe about a third of people will have some nausea when they first start taking the medication. It was mentioned earlier that taking the medication on an empty stomach is ideal for making the medication as effective as possible, which we often think to being at least half an hour before you a meal, or at least an hour after you eat a meal. So, if the meal is the event, the medicine should be at least a half hour before, at least an hour afterwards. This is especially the case if you're going to be having a protein heavy meal, like eggs for breakfast or chicken for dinner, because proteins in the diet are broken down into amino acids, which are transported into the body by amino acid transporters. Well, levodopa is also transported into the body by amino acid transporters. And so, if your gut is busy working on the steak and eggs that you had for breakfast, then some of that levodopa may pass right by the first part of the small intestine without being absorbed.

But what you can do if a nausea is really a significant problem, is you can take it with a little bit of non-protein heavy foods, so crackers or fruit or some juice, that can sometimes help to settle the stomach without reducing the effectiveness of the medication. And within a week, lo and behold, he gets what we want. He has significant improvement in his tremor, as well as in his coordination. So, as we go along over time in Parkinson's, it often becomes a matter of what's bothering you. What are the tools in the toolbox that we have to treat that? And what are the pros and cons of utilizing those tools? So, in our case, after a few months, he notices that his tremor has improved, but it's still bothersome some of the time, especially when he's stressed. Like if he's giving one of those presentations with a laser pointer.

And so, what might we do? He's on this dose of carbidopa/levodopa, three pills a day, kind of the standard starting dose. Well, increasing the dose would be one reasonable option or another option would be adding a medication from another category. Dr. K touched on what is a really important point in my mind as well, which is that there seems to be a tipping point where Dr K mentioned 400 milligrams a day, which is four pills. It seems like if you go from three pills to four pills of the carbidopa/levodopa, then you've crossed that tipping point and the complications of dyskinesia and fluctuations, though that time horizon of those complications comes a little closer. So, what a lot of us would do is, symptoms are very bothersome. Let's start a very effective medication, but let's maybe only start with three a day of Sinemet and not just ratchet the dose higher and higher, but maybe use one or two other medications to all work together so that we can stay shy of that tipping point where the complications come closer on the time horizon.

So multiple approaches can be helpful here. If we started levodopa first, as we did, then adding a dopamine agonist could be helpful. Or if someone had started a dopamine agonist and they're still having bothersome motor symptoms, then levodopa might be added second. Or we might add a booster to carbidopa/levodopa, or lastly, we might add amantadines. So, let me talk about each of those a little here. So, when we talk about boosters, I mentioned the MAOB inhibitors, as already mentioned, these are, this enzyme is involved in dopamine recycling, and not only can MAOB inhibitors be used as initial treatment with a mild benefit, but they can be used often with good effect in combination with other medications, in combination with levodopa, or in combination with a dopamine agonist to improve overall treatment of motor symptoms. And also, if a person has started to develop some of the kicking in and wearing off, these MAOB inhibitors can help extend and prolong and improve the potency of the effect of the first medication such as carbidopa/levodopa.

There's another category of boosters. These are called COMT inhibitors. So, catechol-o-methyl transferase is another enzyme. This one is involved in the breakdown of levodopa. So not dopamine, but this precursor itself, that is part of carbidopa/levodopa.



So COMT inhibitors are only used in combination with carbidopa/levodopa because they don't have any effect on their own. The options for COMT inhibitors are several, but the most widely used is entacapone or Comtan®. And this is available as a separate pill, or you can actually get combination pills, several different strengths that have carbidopa/levodopa and entacapone all in one pill. Well, if we sometimes use Sinemet as a shorthand for carbidopa/levodopa, we are also guilty of sometimes using the old brand name of Stalevo® for the combination for carbidopa/levodopa and entacapone, which is probably in the running for longest combined name of any medication that's used in the field of medicine.

A couple of unique side effects to be aware of for the COMT inhibitors, particularly, and entacapone, a few people will actually have diarrhea, not actually constipation, which is so common, but maybe 4 or 5% of people will have bothersome diarrhea as a side effect and these tablets tend to be orange because of an inactive ingredient. And so, they have a tendency to turn some of your bodily fluids, orange. So, your urine, for example, might not be the color that you're used to. And this is just because of this inactive ingredient in the pill. It's not dangerous, it's not a problem. But it is something to be aware of so that you're not freaked out by it.

The last medication that I would like to mention in this overview of the medications that we might use early in the course of Parkinson's is amantadine. So, like several of the other medications that I've mentioned, it can be used either alone or in combination with other Parkinson's medications. Like what we've talked about throughout this webinar, what we're trying to do if we're using it in this case is treat tremor, stiffness and slowness. In more advanced Parkinson's, amantadine also has a special role because if a person has developed dyskinesias, amantadine is really the only medication that can provide you with more treatment for tremor, stiffness, and slowness, without getting more dyskinesias. Amantadine can actually treat or reduce the amount of dyskinesias that a person may experience. Like some of the dopamine agonists, amantadine also has some specific side effects that may limit its usefulness over age 65 or over age 70. It has what we call anti-cholinergic side effects, which can include dry eyes, dry mouth, worsening of constipation, and sometimes even hallucinations as a side effect. So, what do we do for Mr. Clay? He continues to take carbidopa/levodopa three times a day. And in addition, he adds rasagiline, one milligram once a day. And with this combination, he has better tremor control than he would from either medication separately on its own.

And as time goes along, depending on whether he's having tremor or hopefully only years later, dyskinesia or other motor symptoms, we might be looking at adding or increasing medication as the situation warrants.

So, to recap the action steps from this webinar, I would say to maybe take some of the information that you've gained here, or from the full-length medication webinar that's

available online to discuss with your provider, whether to start a medication or to increase or add medication. Keep an up-to-date medication list and if medication cost is something that you want to be more educated about, or if you're having a medication that is more expensive than maybe your doctor expected it to be, or you expected it to be, you might look at good RX and see if you could get a better deal at a different pharmacy or by surprisingly using good RX instead of your insurance in some cases. So, the optimal treatment will depend on a number of factors, including the symptom severity, age, possible side effects, and so, working with a practitioner who's experienced in treating many people with Parkinson's that we've seen these nuances of how these different strategies play out can be very helpful.

So, I think we have some time for questions at this point. So, thank you very much.

Mel Dizon:

Excellent. We do have questions. So, can the carbidopa/levodopa help with cramps in the feet and calf and even the stomach and, what is going on in people that feel that sort of cramping in the stomach?

Aaron Haug:

Yeah. So, I would address those two types of cramps separately. So, cramps in the feet and the legs is often a Parkinson's symptom that we call dystonia, and that is more likely to occur when a person's medications are wearing off. And so, carbidopa/levodopa, or all of these other medications potentially can reduce cramps by reducing the amount of off time or the amount of motor symptoms that a person has. If the cramps fail to respond to that, then we sometimes have more advanced treatments such as using muscle relaxant medications, or sometimes doing injections of muscle relaxants, like Botox, directly into the leg muscles. In terms of the abdominal cramps. That's a different set of concerns that may relate to the fact, like Dr. K was mentioning, that the stomach can kind of become sludgy due to the slowing of the GI tract that occurs as part of Parkinson's and sometimes worsened by medications. So, treating constipation is important there, and sometimes side effects of medication can be abdominal cramps kind of on the spectrum of also causing nausea. And so sometimes taking it with a little bit of crackers or non-protein food, like we talked about could be helpful or taking less medication at each time, spreading it more times throughout the day. There's a number of strategies that might be considered.

Mel Dizon:

Okay, great. So, a couple of you will have asked questions related to fatigue, and then you mentioned excessive daytime sleepiness or sleep attacks. So, first of all, can you talk a little bit about what's going on with the fatigue, for somebody with Parkinson's? And then somebody is asking, do dopamine agonists cause side effects in people who

already have that daytime sleepiness? Is that something that would prevent you from prescribing it to somebody who's already challenged with that?

Aaron Haug:

Yeah. Fatigue is a big challenge for many people with Parkinson's. And when we talk about fatigue, we mean a decrease in energy. So, it's not exactly the same thing as sleepiness, although they often co-exist, but sometimes people say, I just don't have the get up and go that I used to have, or the motivation to do what I used to do. And so that's fatigue and unfortunately fatigue has been studied somewhat and all of the treatments that we have, have been somewhat limited in their usefulness for treatment of fatigue. So sometimes what's important is a matter of energy conservation management and prioritization and timing your most important activities for when your energy level is best. It is also important to address sleepiness. These two things can exacerbate each other. And so, if a person is not sleeping well at night, we treat the insomnia, or if they're having restless legs, that's keeping them up at night or acting out their dreams throughout the night and that's impairing their sleep quality, there are different treatments available for all of these things. And the Davis Phinney Foundation has other great archived webinars about treatment of the non-motor symptoms that are easily accessible on YouTube and other places. In terms of, if someone is already sleepy, would that make us lean away from a dopamine agonist? It would. So, if excessive sleepiness is present, despite looking for, and treating sleep apnea and insomnia, if someone is already asleep throughout the day, then that would be one reason to potentially use more of levodopa, less of a dopamine agonist.

Mel Dizon:

Okay. Right. So, let's say you're somebody who's newly diagnosed and you're taking carbidopa/levodopa. After five years, is there still the ability to try to get great quality of life with other treatments? I mean, what does it look like if you've kind of run that course with carbidopa/levodopa and it's just a constant machine that you're trying to feed all the time. How can you retain quality of life long after you started with meds?

Aaron Haug:

Yeah. So, I would say that the way that most of us think of carbidopa/levodopa is that it is the cornerstone of treatment. And so, after years, a person may develop dyskinesias or fluctuations, but we usually continue to use that cornerstone of treatment because it is the most robust medication for the tremor, the stiffness and slowness. And if a person is starting to have more fluctuations, then we might buttress that with the boosters or with some amantadine, if there's dyskinesias. It is not that the medication stops working after five years, the carbidopa/levodopa is still the best medication that we have, but we sometimes need to augment it and buttress it with additional medications to try to fine tune and optimize a person's motor ability throughout the course of the day.

Mel Dizon:

Do any of these drugs actually slow the progression of PD?

Aaron Haug:

I wish that they obviously did. I wish we had good evidence that showed this medication not only makes you feel better. It also slows the progression. The one thing that does have evidence that it slows disease progression is exercise. And so, what I will often say is that the medications can make it easier for you to move, and then you have to move. There were a couple of trials where the medications almost showed that, oh, this does slow disease progression. And one of those was for rasagiline, one of the MAOB inhibitors, and so I will sometimes think, well, because it maybe slows disease progression if we're going to be using it for other reasons, or for kind of in a 50/50 situation, but when a couple of options that might lead me towards adding that sooner rather than later, because maybe it does, but the science hasn't ever really been able to show it conclusively.

Mel Dizon:

Great. And one thing to mention, we're going to mention this at the end, and I think you touched on it, so Leigh can put something up, but one of the things for quality of life obviously definitely depends on your age, depends on lots of different factors, but if you're getting to the point where the medications, they actually did work really well to handle the motor symptoms. You know, DBS, deep brain stimulation is a possibility, right? Where you get something that you're not having to take as many meds and it can preserve your quality of life for a really, really long time. Again, lots of different things to think about there, we're going to put up some links so that you can get more information about DBS and all of that, but also definitely talk to your doctor about it. One thing I definitely want to touch on just cause a lot of people have asked over the time, is it safe to get a COVID vaccine when you're on Parkinson's meds?

Aaron Haug:

The answer is definitely yes. And I've had hundreds of people ask me if they should get the vaccine. And I've said yes to every single one of them. There is not anything about having Parkinson's or about being on Parkinson's medications that would make me change that answer. So, everyone, please get your vaccines.

Mel Dizon:

Great. Great. Let's see. Somebody said they were prescribed clonazepam at night after taking carbidopa/levodopa 1.5, four times a day. Why don't you talk about that? Why would somebody be prescribed that?

Aaron Haug:

Yeah, so, I showed that busy slide that had two dozen or three dozen medications listed on it. And that's all just for the motor symptoms of Parkinson's the slide for available treatments for the non-motor symptoms of Parkinson's would be three times that size.

And clonazepam is one of the tools that is often used for a number of non-motor symptoms. There is a motor symptom that it can help with that sometimes can help with tremor, can sometimes help with dystonia or cramps, but it is a sedating medication. So, we often use it for insomnia or to treat REM behavior disorder, which is the dream acting out at night or restless legs. So, it a medication that has several potential benefits especially in the non-motor symptoms domain.

Mel Dizon:

Okay. Somebody is asking about crushing up pills. Is it okay, for any kind of pill that you're getting for Parkinson's, is it okay to crush it up, taking it in a smoothie? I mean, obviously we just talked about the issue with eating and not wanting to do that, but for people that have swallowing problems. So, is it okay?

Aaron Haug:

It depends on the pill. To talk about carbidopa/levodopa as kind of the most widely used and most important one for most people, that one can be crushed. And if you're having delayed ONs or these motor fluctuations, crushing it can sometimes speed that absorption by 10 or 15 minutes as can taking it with a tall glass of water or a tall glass of carbonated beverage, ginger ale, or a taller glass of acidic beverage, like orange juice. Those are all things that can help make carbidopa/levodopa work faster. There also is a oral dissolving tablet formulation of carbidopa/levodopa, which used to be called Parcopa® some of the other medications that will depend whether they can be crushed, especially if you're on any extended release formulation of carbidopa/levodopa or a dopamine agonist, those typically should not be crushed. So that would be something to discuss specifically with your provider who's prescribing them.

Mel Dizon:

Okay. Great. Quick question. Did you say that you did not recommend or rasagiline as a solo med?

Aaron Haug:

I don't think I said that. I wouldn't have meant to have said that. Rasagiline can be used as a solo medication. It tends to have kind of a milder benefit. I will sometimes say that if Sinemet is 10 out of 10 on the efficacy scale, I usually give the rasagiline, Azilect, or the other MAOB inhibitors, like a 4 out of 10. So, they certainly have a role. They can still benefit motor symptoms and they often have fewer side effects. But if a person only has mild motor symptoms, then they can be used early as a solo therapy.

Mel Dizon:

Okay. Okay. Last question. Like I said, we have a lot more content with Dr. Haug. We'll send those to you for anything that we didn't get to today. There's a lot of great content. So, a couple of people have asked this question about how much can you vary the timing of your daily doses? Let's just say it's carbidopa/levodopa to match an active

lifestyle. So, a couple of people have mentioned that each day looks different and they might not take their pills at the same time each day. Is that an issue?

Aaron Haug:

I would say that there's a couple of different ways. This comes out particularly for people that have been on medicine and have had Parkinson's for a few years. And sometimes they say, I don't notice if I miss one, is that a problem if I miss one? It doesn't seem to matter if I take them three hours apart or eight hours apart, I just kind of feel fine. I kind of feel the same all day long. Especially because there's now more advertising about OFF fluctuations, because there are some new, some expensive medications specifically for the treatment of motor fluctuations. I have to tell people it's kind of a good thing that you don't feel your medicine kicking in and wearing off. That means that you're still buffering enough of your own dopamine that the medication just kind of works all day and it's not crucial whether you're taking it four or six or eight hours apart, we may have to deal with kicking in and wearing off a few years from now and we'll cross that bridge if we come to it. Then if a person is noticing, boy, my medicine normally lasts five hours, but if I'm out skiing, it seems like it only lasts three hours. This is a common experience that people have, and you'll need to tailor a program with your prescriber of, well, can I take an extra one or two of my medication on those days? That's where maybe yes, but that would be important to get an individualized response from the prescriber for.

Mel Dizon:

Okay, great. Well, as usual, this is fabulous. Thank you so much. You're so clear and practical and articulate, and it's so much what people need as they're starting to learn about Parkinson's and just could not thank you enough for being here with us today as always. So, thank you.

Aaron Haug:

Thank you very much for having me. It's a pleasure

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