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Larry Gifford: Hello, I'm Larry Gifford, a proud member of The Michael J. Fox Foundation Patient Council, host of another podcast called "When Life Gives You Parkinson's", and co-founder of PD Avengers. We're building a global alliance of people to end Parkinson's, join us at pdavengers.com. Have you ever felt like Cinderella at the ball at the stroke of midnight? Just as the carriage is regressing to a pumpkin, the footmen are returning to mice and the ball gown hangs and tatters off your body revealing your true reality? Your world slows and stiffens, your speech is garbled, your voice is muted, fear kicks in, heartbeat quickens, the right and left hemispheres of your brain stop cooperating with each other. It's as if my brain is shutting down, my body extreme rigidity kicks in and my brain goes into fight or flight, misinterpreting a signal that I'm in danger. For some it triggers extreme emotions from rage and fear to sorrow and crestfallen.

Larry Gifford: The feeling could be a sense of despondency, apathy, out of sorts. Whatever it is for you, it's a gut punch. As you probably have figured out already, today we'll be discussing Parkinson's "off" time. How your experience of "off" time and my experience of "off" time and any other persons with Parkinson's experience of "off" time is completely different. And when Parkinson's goes from "off", to "on", to "off", to "on", to "off", what steps can you take to manage it? Joining me is an amazing panel of professionals and just people with Parkinson's, Dr. Ashley E. Rawls MD is a movement disorder specialist at the University of Florida, Norman Fixel Institute of Neurological Diseases. Soania Mathur is an MD and person with Parkinson's, co-chair of The Michael J. Fox Foundation Patient Council, diagnosed at the age of 27. Rick Schwartz is a person living with Parkinson's and he experiences "off" time. He also is a Michael J. Fox Foundation community member, lives in Vail, and you may remember him as a former professional baseball player and sports reporter. Welcome, to all of you.

Rick Schwartz: Thank you.

Soania Mathur: Thank you, Larry.

Ashley E. Rawls: Thank you for having us.

Larry Gifford: I want to thank some of our sponsors today before we dive into the discussion for making this episode of The Michael J. Fox Foundation Parkinson's Podcast possible: Acorda, Amneal, Kyowa Kirin, Neurocrine and Sunovion. Now let's start by defining "off" time, and for that, Ashley, what is "off" time?

Ashley E. Rawls: So for our patients with Parkinson's disease that experience "off" time, that can be when their medications have worn off between doses. For example, the dopamine treats resting tremor, stiffness and slowness, and when you're in between these doses and the medication wears off, those symptoms can return. But, you could also have other symptoms as well. For example, increased anxiety and also freezing of gait as well. So it's different for different people, but usually that's what we define as our "off" symptoms that occur in between the doses that the patient would take. Initially, many people may not experience the "off" time, but as the disease progresses, usually patients do notice that as the fluctuations continue, they will have times when their medication works very well, and they have extra movements that we would consider dyskinesias, but then they also have where the medication decreases or even stops working that we consider those "off" times.

Larry Gifford: Great. Now Rick, you say you have them all, all those symptoms. Talk me through an "off" time.

Rick Schwartz: "Off" time for me is... After 21 years of being diagnosed the last couple of years, I started really noticing the difference. First 15, 16, 17 years, I was pretty lucky and I have too many symptoms every once in a while, but now it's like it just hits me within three or four minutes sometimes. I'll be feeling pretty good and then suddenly I get a buzz in my head and I stop walking, I'm shuffling, my face becomes a mask. I feel like I'm going within myself, and I have to sit down and wait until it goes through. And now it's becoming more and more, it used to be sort of a pattern. I take the drug at 8:00 in the morning around 11:00, and I would start going downhill.

Rick Schwartz: So I take one at 11:00 and 5:00, but now I take it and it doesn't matter. Sometimes I freeze at 9:00 in the morning, sometimes I don't freeze at all, it's just a hodgepodge. And when I'm in that throes of being "off", I can't do a darn thing. I just have to sit there and wait it out. And when I feel "on", I still feel like I'm 35 years old and can still throw a curve ball, you know? I mean, I feel good, I feel great when I'm "on". When I'm "off", I feel like I'm 100. I feel like I'm two different people at this point.

Larry Gifford: Soania, what's your experience with "off" times?

Soania Mathur: Mine is a little bit similar, I've been now over 22 years since my diagnosis and for the first while, I really didn't have that experience, but probably in the last two or three years I've noticed that usually prior to my next dosing, I'll experience some "off" time. At times, it's maybe a little bit more spontaneous than that, but usually I can look back and see that I either hadn't gotten enough sleep or there's something stressful that happened that maybe triggers my next day.

Soania Mathur: My "off" time is primarily motor-related, meaning I start to slow down, get very stiff, tremulous. I do have sometimes a little bit of anxiety at times and apathy, and I kind of measure my "off" times more in terms of functioning. So if I'm not able to get through an activity that I normally get through, I know that I'm pretty much "off". Because it's predictable, I do things like make dinner in the mornings, because I know evenings are probably more "off" time than not.

Larry Gifford: A lot of salads because it's going to get cold by dinner.

Soania Mathur: I can reheat it.

Larry Gifford: Yeah, I was diagnosed four years ago and I experience "off" times and my wife calls it 'when I'm in my bubble.' So I'll be sitting in a chair and I will just be in my own little world, and I won't notice that our son needs help with something. I won't hear her calling me from the kitchen. I'm just of sort of frozen in my own little zone. But if I do get up, I'm shuffling my feet and it's hard to balance, everything sort of becomes very rigid. And then yeah, it is disconcerting because it feels like you're regressing in fast forward. Like if it was a tape player and you had a rewind and a fast forward in a regular play, or on your podcast where you can go from regular speed to x2, it feels like the Parkinson's has just hit x2. Ashley, is that how you've seen patients define it?

Ashley E. Rawls: Yes, so many of my patients have told me that it feels like they're walking through molasses or that they get stuck, sometimes there can even be a trepidation or an anxiety where the "off" times come unpredictably, like it was described before where they could be walking across the street and suddenly there's an "off". And that can really become very troublesome and problematic with trying to go about your daily life. So, many of my patients have described it as that. And then some of my patients who may not have as much motor symptoms can describe their "off" as an increase of anxiety, this rush of "I'm looking for my next medication, I feel like there's something going on inside of me, but I have a lot of difficulty describing what that is." So it could be both motor and non-motor symptoms that people experience, and it's definitely up to the provider to try to tease those out every time that they meet with one of the persons that have Parkinson's disease.

Larry Gifford: To back that up, there was a published paper in movement disorders in 2020, examining how people with Parkinson's experience "off" time and the paper used data from The Michael J. Fox Foundation's clinical study: Fox Insight, which I'm part of, and you should be too, Fox Insight, look it up. Study found that the three most common of the "off" symptoms were freezing of gait, apathy, and memory problems. So as you said, Ashley, it can present itself as a mix of motor and non-motor symptoms.

Ashley E. Rawls: Yes.

Larry Gifford: The study also found that some patients had trouble even explaining their symptoms and nearly half described bothersome symptoms that would be missed by a standard assessment conducted by doctors. How can a person with Parkinson's, or even their partner, talk to their doctors about this topic in a way that they would understand it? I'll start with Ashley and I'm going to go to Soania, and maybe Rick has some thoughts on that too.

Ashley E. Rawls: OK, that's an excellent question. And like I said before, I think it's up to the provider to really delve into that when we're doing our general overview during our follow up appointments with each other. So, many times what may be helpful is I ask about two different things: the "on" times, the dyskinesia, the wiggly movements, how you feel when you feel your medication is kicked in, and then I specifically ask, what are your "offs"? And many people have difficulty telling exactly what their "offs" are, it may be very nebulous, it may be something they can't really describe. What I usually ask people to do and also their family members is by saying, "Make a motor diary and make very quick bullet points of what happens through you throughout the day, both the extra 'on' symptoms of wiggly movements and the potential 'offs' of increased stiffness, slowness, some tremor." If the patient really doesn't have as much insight into these potential "off" symptoms, a lot of times I will add-

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Ashley E. Rawls: Insight into these potential off symptoms. A lot of times I will ask the caregivers or the family to say, do you notice when this, when the, your family member, your loved one is, you can tell when they're ready for their next dose. And if you say yes, then I ask, okay, how do you know that your family member is ready for their next dose? Do you see it in their face? Do you see them become more anxious? Do you notice that they are more stiff and more slow? And then how long does that occur before a dose? Because that can help with us really pulling out and recognizing what an off symptom may be and then potential management options we can go with from there.

Larry Gifford: You've mentioned dyskinesia a couple of times. Can you help define that for people who aren't familiar with that?

Ashley E. Rawls: Yes. So when we mentioned dyskinesia, these are basically extra non-purposeful movements that can occur when we see that our patients are really, what we call on their medication. So not just improvement of tremor, stiffness, and slowness, but it can almost, as a theme, levodopa replacement can overshoot what you need. And so it can be a purposeless kind of shifting of the head, the shoulder, the arms and legs. That's not usually when it's very mild, it's not bothersome to a person experiencing it, but their feeling members can notice that the person appears to be restless. When it really becomes a more of an issue is when it's a definite, when it keeps someone from walking or engaging in the activities that they wish to do from day to day. So that's what we would define as a dyskinesia.

Larry Gifford: Okay. Soania, you are a physician and you are somebody who with Parkinson's, so you've seen both sides of the coin here. How would you advise people to talk to their doctor about this?

Soania Mathur: Well, I mean, I do agree with Dr. Rawls that the clinician needs to ask the right questions, but I also think in this disease in particular, knowledge is power. So patients have to become educated about what that, the terms that they're going to be using and what information they need to give to the physician, such as when they're dyskinetic. What does that mean? When they have dystonia, what that means. On and off, what that means, because your clinician is going to base their management decisions on based on what they see, but also what you tell them. So all the symptoms that Dr. Rawls mentioned are very important in relation to the timing of your medications, because sometimes you can get dystonia, not just when you're off, but when you're on and sometimes you can get dyskinesia and the other way around too, they're rarer than the normal, but they still can happen. So that kind of timeline of your symptoms versus when you're taking your medication is really important.

Larry Gifford: Rick, what's been your experience in talking to your MDs about this?

Rick Schwartz: I'm doing the symptoms right now. Because I can't stop my head from shaking and all that. So I guess I'm a picture of what it can be at times. I'm on now, I'm ready to go, but I'm moving around quite a bit here. So I was kind of laughing when you were describing the symptoms, but you know, I do a lot of boxing. I just like to do that to stay in shape and help with the Parkinson's and my trainers, because they're so close, they're watching me every, we're working hard. They tell me that they can tell when I'm on and off, after a while. I have three different trainers and each one of them has told me time. I know when to ease off, I can see you're not moving much. And then four minutes later, I'm punching as hard as I can. And we move, and we go right through the workout. So that's- the people who get to know you can see it pretty, I think pretty easily if you have these kinds of symptoms, but-

Larry Gifford: Well, yeah. I mean, I know my wife she'll go, is it time for some medication? Do you experience that too, Rick?

Rick Schwartz: Yeah, yeah, yeah. Linda, my wife knows more about me than I do at this point. The caregivers are unbelievable and yeah, it's, when I'm off, I usually get dystonia, which is much worse than this. When your arm starts whipping backwards and you can't stop, stuff like that.

Larry Gifford: What about you, Soania?

Soania Mathur: Yeah. I mean our, and my husband-

Larry Gifford: Your daughter's too.

Soania Mathur: Yeah. My daughters notice now. So they see me moving slowly, depending on what kind of mood I'm in, they'll ask if they can run and grab my meds, which is very good.

Larry Gifford: Well, Mike, my 12 year old son does that too as well. He'll go, dad, do you need your meds? And it makes them feel like they're part of the solution. It's great to give them a job.

Soania Mathur: Exactly. It's empowering for them to be able to feel like they can do something to help you.

Larry Gifford: What are your conversations with your spouses like when you're talking about on and off? And have you created, one of the things that I've created is I know I'm exhausted at the end of the day. Whether I'm off after five, just because I'm working full time and everything else. And so by five o'clock I cannot answer open-ended questions. So we have a rule in the house that after five o'clock it's yes, no questions. Don't give me, don't ask me what I want for dinner. Give me a choice between two things. Well, how have you approached discussing what you need with your spouse?

Soania Mathur: I think we've spoken about this before, Larry. I'm terrible at it because I don't know half the time what I want from the answer to the question, are you off? Well, yes, I'm off. But sometimes that means I want help. And sometimes it means don't help me because I got to do what I'm doing. And if I don't get through it, I'm going to be frustrated. So, my poor husband has to kind of navigate that uncertainty of what his response should be, but he's very good at it now. He can kind of tell when I'm just being, something that I have to do myself, even though I'm off and I just need to be stubborn about it versus I just really need some help at the moment.

Larry Gifford: Has he asked, do you want help?

Soania Mathur: He can usually tell by the answer to, oh, you seem like you're off. And then depending on what answer he gets, he can usually tell what the answer is.

Larry Gifford: If I'm doing a past like trying to button my shirt and I'm off-

Soania Mathur: Right, right.

Larry Gifford: She'll go, are you, do you need help? I'm like, no, I'll figure it out. And then there's times where I'm off and I'm chopping celery or carrots. And she's like, yeah, I'm just going to take this knife out of your hands now.

Soania Mathur: Wise.

Larry Gifford: What about you, Rick?

Rick Schwartz: I think this is what creates a lot of tension sometimes because sometimes I try to gather things and be ready for my off time, TV remote, stuff like that. Water and all that kind of stuff. And at times, then I'll shuffle over and finally sit down and then I'll see something over the other way I forgot to bring with me and I go, Linda, can you help me? And you don't have to walk, it gets to be old. And I feel bad that I have to ask for things and I don't want to upset her. She's not upset, but you know, it's just the tension sometimes on silly things like that that bother me a lot. That's when I get frustrated, it's like, wow. I just want to get up and get the damn thing and bring it right back. And I can't do it sometimes. That's frustrating.

Larry Gifford: Well, yeah, I mean, I think that goes to, and I think a lot of people with Parkinson's at different times feel like they don't want to be a burden to their family. It sounds like, we've talked about it and she's like, listen, I married you. So this is what we signed up for. This is all part of the deal. This is not burdensome. This is just marriage. But you know, it's still hard to, you still feel guilty or whatever you feel. I oftentimes do. And it's tough, because you want to help. You want to be there and you want to be as independent as you can be, and you want to be there for your kids and you want to be able to do the things that other parents can do. And so for me personally, I won't speak on behalf of you guys, but from my perspective, that's one of the most frustrating parts of the disease is that you cannot plan for family events and everything else, because you don't know how you're going to feel two weeks from today at four o'clock.

Rick Schwartz: No, I don't want to sound macho. I'm really not a macho guy, but all my life, I sort of took charge of things and I was the one who made, did things whenever I wanted to and stuff like that. Now I'm dependent on others. And it's hard sometimes to make that transition from being the man, as it were, work or whatever, and then coming home and that in my world is shrinking because all these off times, it's hard. I went to my niece's wedding earlier this summer. It was in San Diego. And it's so hard to get there because you go to the airport and you don't know what you're going to be on or off. So I get in a wheelchair, you go through all the customs. I mean, by the time I get on a plane, I'm exhausted. So you find you're doing less and less travel, less and less movement. And you know, it's part of life and I can deal with it, but it's just frustrating. That's the biggest thing for me. It's frustrating.

Larry Gifford: Ashley, do you have any advice on how people can handle their off times?

Ashley E. Rawls: Yes. Would you like me to address it from the medication perspective or?

Larry Gifford: Give it all to us. We need everything.

Ashley E. Rawls: Okay. Excellent. All right. So with off times, these are things that can naturally occur when you're taking your levodopa medication. And as the Parkinson's disease progresses, they usually become more and more prominent. So things that can be done to help with off time are one, recognizing them and speaking with your spouse and your doctor to figure out exactly what your off times entail and then how long they last. And if they're in relation to the medications themselves, because that's going to help guide treatment and management with your provider, your Parkinson's disease specialist. Things that can be helpful to making sure that your medication regimen is correct or optimal, I guess you could say.

Ashley E. Rawls: Sometimes we ask our patients if the off times are occurring, for example, an hour before your next dose, sometimes we will recommend moving the dose earlier so that you don't go completely off. That can be helpful. Sometimes we will recommend taking a half tablet of, for example, a Sinemet or Carbidopa-Levodopa the immediate release and chewing it about either an hour or half an hour before your next dose, depending on how long you've been, how long your wearing off times are to bridge you a little bit until your next dose. Some people will recommend taking your dopamine or your, the levodopa replacement 30 minutes before or 30 minutes after a meal.

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Ashley E. Rawls: Replacement 30 minutes before or 30 minutes after a meal, because sometimes protein can compete with the absorption of the dopamine from the Levodopa that you're taking in. And so in order to help with that, to make sure that they're not competing with each other, we try to make our meals a little bit further apart from the actual medications themselves. Sometimes what others can do, what can be considered as taking a longer acting formulation of the Levodopa. For example, there is Sinemet immediate release, or IR, that's what many of my patients are on. They also have a Sinemet CR, which is a continuous release. However, the continuous release, the reason why people don't take that usually as their main Levodopa replacement is because it can be unpredictable, unfortunately. But it's supposed to be slowly released throughout the day. So you and your neurologist could consider taking a continuous release earlier in the day and having it slowly released and then taking the immediate release on top of that.

Ashley E. Rawls: Another thing with that, there's also a formulation that has both a type of the immediate release in the controlled release of Levodopa called Rytary. This is a newer medication that is on the market for the past couple of years and people seem to like that because it gives you the boost that people usually at least explain or look for with the intermediate release of Carbidopa-Levodopa or Sinemet, but also has the long acting form underneath it to help keep you from having so many spikes, so many ons or offs.

Ashley E. Rawls: There are also what we call COMT inhibitors like Entacapone, or Comtan, that are on the market that can help kind of stretch out the Levodopa for probably about 30 minutes or so, that can be taken along with your regular Parkinson's disease regimen to help kind of maybe shave off a little time with those off times.

Rick Schwartz: As time goes on, is it better to take less? Is it better to take more? Does it make a difference as far as, not quality of... But just how much until it all stops working?

Ashley E. Rawls: Okay, so that's an excellent question. So I would not say that the medication itself becomes ineffective. I believe that the disease itself just continues to progress because you're losing the dopamine producing cells in the substantia nigra. So it stands to reason that over time you would need more and more dopamine replacement that comes with it. So I know some people are aversive to medications and may seem like they do not wish to take so much or you're taking the Carbidopa-Levodopa, ending up being every two hours and every hour that can be disruptive for your life. But it is something that I look for more of the quality of life that comes with it, if I may be honest. To me, it's important for you to maintain a functionality so that you can do the things that you love during the day, even though it may be inconvenient with the amount of medications or types of medications that you may take. But again, that's also a discussion that you have with yourself and your family and your provider as well. From my perspective.

Larry Gifford: Yeah. I like that answer. I find that I was not a regular taker of pills. I didn't have any medications that I was taking regularly before Parkinson's and I was hesitant. And then after we've got the Levodopa-Carbidopa correct. Oh my God, I love pharmaceuticals. Just give them to me. I want to feel good now. I don't want to hold off on it. I've just... Without them, I couldn't do what I do, I wouldn't... Before I took Sinemet or Carbidopa-Levodopa, I couldn't type, I couldn't put my hand in my pocket. I couldn't walk very well, I was falling all the time. And then with the right amount of Sinemet, I have all that back and you do a lot of exercise too in therapy, but I didn't realize when I was diagnosed that I could get some of that functionality back. And with the medication and physical therapy and occupational therapy, I was able to do that. And that was exciting to me.

Soania Mathur: Yeah. I think that's a really important point, Larry. I think that we have to make sure that people understand they don't have to be afraid of medications, because until there's a cure, some sort of drug that can modify this disease, it's all about quality of life as Dr. Rawls was saying. So taking the Sinemet or Carbi-Levodopa, if it helps you feel better and makes your life more enjoyable and you can function better then that's worth taking.

Larry Gifford: Do you Rick or Soania have any tricks that you do when you're off? Is there anything that always works or sometimes works or things you try all the time?

Soania Mathur: I do what Dr. Rawls mentioned. I've tried other sort of rescue medications, but what works for me the best is chewing a Sinemet. So taking it sometimes with something carbonated so it absorbs faster and just waiting it out. But also for me, Larry, it's about preventing them in the first place, because I know mine are fairly predictable. That means I have to take my medications on time, which I think after all this time would be easy, but no it's not. I often am delayed with my doses.

Larry Gifford: Why is that? I set timers, I...

Soania Mathur: I don't know what it is. Anything else seems more interesting than taking your medication, I guess. But also preventing it with self care things, like making sure I get enough sleep, making sure I exercise first thing in the morning, because that seems to help me stretching out these sorts of things that I know will sort of hopefully make it less likely that I experience an off time is something I try and schedule in as well.

Rick Schwartz: I'm one of those that doesn't like to take the medication not because I'm afraid of it, I understand the concept, but for me it's maybe psychological. I feel like if I can just exercise and get some sleep, I have a good day usually. If I don't sleep much and I didn't get exercise hard I have bad days. So to me, it's like the drugs are secondary for my life and what I think works for me. Exercise and sleep to me is what's keeping me going.

Larry Gifford: Did you ever ice your arm as a pitcher?

Rick Schwartz: All the time, yeah-

Larry Gifford: Why would you do that?

Rick Schwartz: Say again?

Larry Gifford: Just suffer through it. You can get through, you can man up.

Rick Schwartz: My nickname in baseball was bulldog and that sort of sums up my mentality. Move on through it!

Larry Gifford: Well, I'm sure you took a few pain pills too.

Rick Schwartz: I didn't.

Larry Gifford: No? You should have, this is what I'm telling you-

Rick Schwartz: I'm serious, when I had the... I've had some serious things happen along the way when I've had Parkinson's and because I didn't want to take a lot of medication, I'd take two aspirin for a major surgery. And I just sort of, I don't know, it's dumb. It's crazy maybe, but it helps me. It worked for me.

Larry Gifford: Well, good. Well, whatever works for you, it's about your quality of life more than anything.

Larry Gifford: I do want to talk about going into an off time when you least expect it. I was at a birthday party for a kid across the... one of my son's friends. And I started having an off time and there was all these kids running around and I started getting panicked. And so I just went over to my wife and I said the code word. And then she excused us. I think that's important to have a game plan going someplace, if something goes wrong and you need to get out of there, whether it's by yourself or with your spouse, there needs to be a quick way to say that without drawing attention to yourself, because none of us want to be the center of attention when we're off. But I find that's really helpful. Because I know if I get around too many people or there's too much fast action, that's my anxiety kicks in. Do you have any of those types of tricks or codes or have you guys talked about that with your spouse?

Rick Schwartz: Yeah, I just... They go off, I say "let's get out of here, I'm not doing well." And we go. I mean, that's basically the plan and I don't have any plans beyond that, I guess.

Larry Gifford: Soania?

Soania Mathur: I think I've had it so long that Aaron can kind of can see it before it starts to go. So he'll sort of direct the evening as needed.

Larry Gifford: Ashley, what kind of research is going on in this area to help with the off times?

Ashley E. Rawls: So with off times, which is definitely one thing that comes up several times with our patients in the clinic, on the research that we have going on is trying to figure out how to at least either decrease the off time or make it so that when it does occur, we have an intervention that we can take so that the off time will be much shorter. So things that are currently on the market are going to be Apokyn, which is an apomorphine. Basically it's an injectable that acts very similar to dopamine that we have in our brain, that when someone is off you inject it. And then very shortly thereafter, the person can move a little bit better to the point where they can at least start taking an extra dosage of their med if their next time for their doses is not available at that time.

Ashley E. Rawls: Another one is going to be Inbrija, this is also a newer medication as well. This is the inhaled Levodopa form which I believe is FDA approved back in 2018. This is an as-needed medication that you take along with your regular anti Parkinsonian medication regimen. So if someone becomes acutely off, they can use it. It's basically almost like an asthma inhaler. The dopamine particles are inhaled through the lung, and then it takes about maybe 10 minutes to potentially an hour or so where you have that... where it kicks in in about 10 minutes and you have about an hour's worth of time until your next dose should happen. So these are something that are already on the market, FDA approved that can be used. But again, you got one thing that can be difficult with those is that when you're off and nobody's around you, you may have difficulty giving yourself an injection or may have some difficulty using the inhaler. So what we're looking for is something a little bit easier to use. They have a subcutaneous or underneath...

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Ashley E. Rawls: ...you're to use, they have a subcutaneous or underneath the skin infusion device that actually infuses dopamine, almost like an insulin pump. The subcutaneous dopamine infusion devices are under research protocol currently. Hopefully we should be having some data coming out with that soon, but it looks promising.

Soania Mathur: There's also, Dr. Rawls, the sublingual, I believe, apomorphine as well on the market already.

Larry Gifford: Under the tongue?

Soania Mathur: Under the tongue. Kind of like a Listerine breath strip or something that you put under your tongue, it dissolves, and it's supposed to give you relief as well. I don't know specifics of what's coming down the pipeline, but those are sort of the broader categories as Dr. Rawls mentioned.

Rick Schwartz: There's something I'd like to mention that we haven't mentioned. And I think it's as big as anything else. It's better to have a sense of humor about this whole thing. About life and about Parkinson's. We haven't mentioned that, that to me is huge. It's right up there with exercise for me. If I can't laugh at myself and laugh at what's going on, I think I'd be dead by now, I really do. I know people who sit on the couch, at the end of the couch, feeling sorry for themselves, and two years later, they're not around. You stay active, you have friends and you have a sense of humor about it, you can get by I think, more often than not.

Larry Gifford: Oh yeah, I laugh all the time. We laugh at a break a dish, we laugh. I actually started an improv group for people with Parkinson's and we laugh all the time.

Rick Schwartz: Yeah. It's important, I think.

Larry Gifford: It's all part of the quality of life. In fact, when you're with friends you're engaged, you're able to focus on conversation or it could help you create some new neural pathways because you're more engaged than maybe you typically are. Because you have to be alert and aware of what they're saying in order to respond to them. You have to... You try to use your facial expressions more. If you're laughing, you're actually stretching those out. So your frozen face becomes a little less frozen. Laughter is great for a lot of things.

Rick Schwartz: Yeah, I agree with all of that. It's important to me, I know that.

Larry Gifford: Well, I know you make me laugh.

Rick Schwartz: It's my looks, right?

Larry Gifford: I go: "Look at him, look at that guy."

Rick Schwartz: I can take it Doc, I can take it.

Larry Gifford: All right, so any final words about off-times before we turn this podcast off?

Soania Mathur: Just that, it can happen with time or depending on the individual's disease experience, but it is something that can be managed. It's not something that you necessarily have to live with. You just have to recognize it or your care partner has to recognize it. And you have to express that to your physician or your medical management team. And hopefully they can improve it, because the issue is the quality of life. These can really adversely affect your quality of life if you don't get it taken care of.

Larry Gifford: Rick, any other final words?

Rick Schwartz: Yeah. I think, like I said to me, maybe it's good to be simple minded like myself because it makes it easier to think through things. And I just think, again, you do the best you can. Satchel Paige was a pitcher for the Cleveland Indians and he was in the old Negro Leagues for years. He's an easy one. And he said: "I never look back because someone may be gaining on me." And this way I look at it, just keep going forward as far as you can, as long as you can, and when you stop, you stop. That's it, you're dead, to be honest with you. So I go as far as I can, as long as I can, enjoy life as best I can. And I think that's what gets me through.

Larry Gifford: That's great. Dr. Rawls?

Ashley E. Rawls: Yes, I would say for final closing thoughts that the off-times can be just as important as your on-times. So really understanding what is going on in your body. And if you have difficulty seeing that, then asking your family members can really be helpful in helping to manage your care. Because I know that many times you come into the clinic, you have your half an hour or you talk about different things. You try to get your regimen as straight as you can, but you really want to bring this up with your physician if they do not actively bring it up with you for whatever reason.

Ashley E. Rawls: It may take some introspection and don't be afraid to ask your spouse or your family members to chime in, to help us try to identify not just the on symptoms of when you're doing really great, but also the off symptoms so that we can, so that you and your family and also your care team can discuss potential options to really enhance your quality of life. Because that to me is the big thing with my patients, is giving you the best quality of life to allow you to live out your daily functions with the optimal treatment that we have available.

Larry Gifford: Would it be helpful to take video of the off-times, so that you can see what they're trying to say?

Ashley E. Rawls: Yeah, so as a movement disorder specialist, we love videos. So that's really helpful as well to take a video to show what is going on, because sometimes the medical terminology that we use on the physician side doesn't quite correlate to what the patients may be experiencing, or how the patient or family describe what's going on. So showing a video saying, yes, this is what my off time looks like, can really help us visualize exactly what you mean. And so then say: "Oh yes, this is definitely an off-time, this is a dystonia." Some people can actually get off dyskinesias or off wiggly movements. So those are things that are helpful to us: "Oh, this is you're freezing of gait." So that we can help put everything into context and then make a plan together on what would be the optimal treatment.

Larry Gifford: I'm just going to add here as we close up. If you're like me and a once a week you sit down and just sort out all your pills and do a big pill box, it has like 16 different slots for four times a day or whatever. Don't do that when you're off, because you'll end up with more medications than you know what to do with, or you'll end up on the floor. So now it's gotten to the point where my wife sits down there with me and she closes each slot as I go along and make sure I do it right. And that's really, when we talk about partners in Parkinson's, it's not necessarily, she's not my caregiver, but there are things that she can help me with. And so there are... I really appreciate that about Rebecca and how she's embracing the role and helping me when I need it, and then giving me space when I don't. Or asking me: "Do you need help? Do you not need help?" It's a constant... As the disease progresses so should your conversations with your spouse and your doctor.

Larry Gifford: All right, so thank you, all of you. Rick and Soania, and Dr. Rawls. This has been a very insightful and cathartic, I think too, Rick don't you agree?

Soania Mathur: Absolutely.

Rick Schwartz: I agree.

Larry Gifford: Also, remember to set your pill timer, so you're not late for your Levodopa. If you want to learn more, there are some great videos, blogs, and webinars at The Michael J. Fox Foundation website. Just go to michaeljfox.org/off. On behalf of my guests and all the hardworking people at The Michael J. Fox Foundation who are here until Parkinson's isn't. I'm Larry Gifford. I'll talk to you next time.

Speaker 1: Did you enjoy this podcast? Share it with a friend or leave a review on iTunes. It helps listeners like you find and support our mission. Learn more about The Michael J. Fox Foundation at michaeljfox.org. Thanks for listening.

Michael J. Fox: This is Michael J. Fox. Thanks for listening to this podcast. Learn more about The Michael J. Fox Foundation's work and how you can help speed a cure at michaeljfox.org.

PART 4 OF 4 ENDS [00:41:56]