Michael J. Fox:

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Speaker 1:

Welcome to a recap of our latest Ask the MD video. Tune in as a movement disorder specialist at The Michael J. Fox Foundation answers your questions about Parkinson's research and care. Learn more about living well with Parkinson's disease. Free resources like this podcast are always available at MichaelJFox.org.

Rachel Dolhun:

Hi, I'm Dr. Rachel Dolhun. I'm a movement disorder specialist and lifestyle medicine physician at The Michael J. Fox Foundation for Parkinson's Research. Today we're going to be talking about medication for Parkinson's Disease. This is a topic that so many people and families wonder about whether they're new to Parkinson's or have been living with it for some time. Early on, the questions are around, "Do I have to take medication?" Or, "When should I start it?" Or even, "Will it cause side effects like dyskinesia?" And after a few years, those questions become more like, "Why doesn't medication seem to work as well?" Or, "What else can or should I be doing?" I'll answer these questions and more. I'm hopeful that you'll learn new and useful information throughout.

If you've recently been diagnosed with Parkinson's, you're probably feeling pretty uncertain or worried, and that's completely understandable and very normal. You also probably have a lot of questions, and many of those may be about medication, so let's break it down. Here are three key facts to know about medication when you're getting to know Parkinson's.

First is that all currently available Parkinson's medications treat the symptoms of Parkinson's, and they do that very well, but none has yet been proven to slow or stop the natural and gradual change that happens with Parkinson's or what we call progression.

Now at the same time, there are many trials that are testing therapies with the potential to slow or stop progression, and others are studying how disease comes on and changes, so we can develop better treatments. These studies need volunteers who have recently been diagnosed with Parkinson's and are not yet taking medication. So before starting treatment, you might want to talk with your doctor about whether participating in research may be an option for you, but you also don't want to delay medication if you need it.

What I always say is start medication when symptoms get in the way of anything you want or need to do. Now that could be giving a work presentation, exercising, which is so good for Parkinson's, playing with your grandkids, going out to eat with your friends, traveling, any other activity that's important to you and that Parkinson's limits.

The next thing to remember is that medication is only one part of your Parkinson's treatment. Now, some people need to start medication right when they're diagnosed. Others can wait a little bit longer if their symptoms are really mild, and they're not interfering with their life. Like Parkinson's, it differs so

much from person to person, but no matter when you start medication, there are things you can and should do right now in your everyday life that can help you manage Parkinson's.

One of the best is exercise. Exercise can lessen your symptoms, it can help you move better, make your medication work better, it might even slow the progression of disease over time. And any kind of exercise works, walking, running, cycling, boxing. The best exercise is the one that you'll do, so find something or a couple things that you enjoy doing and you'll do regularly.

Along with exercise, you can eat a healthy diet, one that's full of fruits, veggies, whole grains, and not as full of processed foods, meat, other less good or less nutritious items. You also want to try to get good quality sleep and lower your stress as much as possible. I know that's easier said than done for a lot of us, but there are many calming and relaxing activities like meditation, mindfulness, yoga, that might help.

And last but not least, build positive relationships with your loved ones, your friends, colleagues, and when you're comfortable with the Parkinson's community. These interactions can help you from feeling lonely or isolated, and they can be support, motivation, or inspiration for life with Parkinson's. Plus, they're just generally good for your brain and your thinking.

The last thing I want you to take away about medication is this. Don't be afraid of it. Parkinson's medications work very well for many symptoms, especially early on. They might not yet be able to slow disease, but they also don't speed it up, and they don't always cause complications.

One complication that a lot of people worry about is dyskinesia, which is involuntary movement. Some worry so much that they hold off on taking medication long after it could be helpful for them. Now, it is true that dyskinesia can happen after many years of both living with Parkinson's and taking medication, but it doesn't happen in everyone, and even if it does, it's not always really significant or really bothersome, and we can treat it. There are several dyskinesia treatments that are now available and more on the way.

Now, maybe you're curious about what might happen after taking medication for a couple of years, or maybe you've already been taking medicine for a couple of years, and you have questions about your experience. So let's talk about how medication benefit and needs might change throughout life with Parkinson's. Here are three key facts to keep in mind.

First, as Parkinson's changes, medications may need to change too. Now, that doesn't mean your medication has stopped working. It's a common misconception that you'll only get a few good years with medication, so you should hold off until you really need it, but the truth is that if medication works, it will always work, so you might be asking, "Then why doesn't it feel like it still works?" Or, "Why doesn't it last as long or take away my symptoms as well as it once did?" That's the disease changing over time. As Parkinson's progresses, it can bring more or new symptoms, and the gap between Parkinson's and what your

medications can cover widens, so you need more or different medication or even other treatments to help bridge that gap. Now, I want you to know you're not doing anything wrong, and your medication hasn't stopped working. It's just that as life with Parkinson's evolves, your treatment evolves too, and that's normal, and that's expected.

Second medication can sometimes, unfortunately, fall short. The reality is that medication can't yet treat all of the symptoms of Parkinson's. I don't want to sound discouraging, but I also don't want to sugarcoat things. As disease progresses, especially after many years or even decades, it's more likely to bring some of those truly bothersome and difficult to treat symptoms. These could be things like trouble swallowing, difficulty with balance, falls, even significant memory or thinking changes. Some of you might be experiencing these challenges now, and we recognize the impact that they have on you and your loved ones. That's why the Michael J. Fox Foundation is focusing on research to better understand and treat these symptoms as well as on developing better medications, finding new approaches, and leveraging technology to fill in these gaps.

And in the meantime, it's where treatments outside of medication may help at least somewhat. There's speech therapy to help with swallowing, physical and occupational therapy to make walking a little safer and easier, and support groups and others in the community who understand what you're going through and can offer their own tips and solutions.

Finally, your Parkinson's treatment regimen will be as unique as you are. There are many medications and other treatments for Parkinson's. Finding the right ones for you, for your motor and non-motor symptoms, for your lifestyle, for your approach to life with the disease, it's often a trial and error process. When working through this process, here's what I recommend. Make sure your doctor is a good partner who listens to you and who you trust. Keep the lines of communication open with your loved ones. They might notice some changes before you do. Stay in tune with your symptoms. If something feels off, talk to your doctor right away. You know yourself best, and when adjusting any of your medications, your exercise, any other treatment for Parkinson's, keep a log to track what seems to work and what doesn't and ask a lot of questions about the latest research, the newest drugs, and other promising tools. Learn as much as you can and be an active participant in your care.

Michael J. Fox has said the latest research is the latest hope, and there is so much momentum and progress and research and so much reason for hope, and it's because of you, our community members, advocates, research volunteers who join us to help push science forward. We see progress in so many ways, including more and more Parkinson's treatments coming to market each year. More treatments means more options, and with it hopefully the ability to better treat more symptoms in more people living with disease.

But with each new drug come questions. For many people, those questions are around, "Should I be taking the newest drug?" And the short answer is that it depends. Now, if you're doing well, and you're feeling good, meaning your

symptoms are under good control, you don't have much in the way of side effects, you can do pretty much everything you want or need to do, then you probably don't need to make any changes, but it's always good to learn more. Here are three questions to ask your doctor about any new treatment.

First, "What does it do? What does it approve to treat?" Second, "How might it help me and my Parkinson's?" And third, "What are the possible side effects? Could it interact with any of the other medications that I take?" From there, you and your doctor can consider other ways a new medication might impact your daily life like how often you'd need to take it, whether it'd replace or add on to the medications you're already taking, how much it costs, and more. This can ultimately help you and your doctor determine whether a new therapy is right for you.

Wherever you or your loved one is with Parkinson's, I want you to know that there are many medications, treatments, and other tools that can help you live as well as possible with the disease. As research moves forward, learn as much as you can, stay up to date, get involved with clinical trials or the community, and of course, stay in close conversation with your personal doctor.

For more on this and other topics in life with Parkinson's, visit our website at MichaelJFox.org.

Speaker 1:

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