Michael J. Fox:

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Speaker 1:

Welcome to a recap of our latest Third Thursday webinar here directly from expert panelists as they discuss Parkinson's research and answer your questions about living with the disease. Join us live next time by registering for an upcoming webinar at michaeljfox.org.

Jimmy Choi:

Hi everybody and thank you for joining us today. I am Jimmy Choi. I am a member of the Michael J. Fox Foundation Patient Council. I was diagnosed with Parkinson's in 2003 at the age of 27. This is my 20th year living with Parkinson's and along the way I've learned some valuable lessons about PD through personal experience and participation with many clinical trials and I have made it my goal to share that knowledge with others. We talk about treatment options all the time, like medication and exercise, but there is a topic that to me at least feels like it's always an afterthought, and that is our diet and our nutrition. I know firsthand how important diet and nutrition is when it comes to managing Parkinson's symptoms. That is why I'm so excited to be joined by this expert panel to discuss one of my favorite things with you all today, eating.

Wait, no. Brain health and food. I think everybody understands the importance of healthy eating for not just overall health, but it's even more important for people who live with Parkinson's. And more and more today we are gaining the understanding of how healthy eating can boost your brain health if you have Parkinson's or if you're worried that you might get it. So our panelists today will discuss ways of improving our brain health through diet. And let me begin by introducing our panelists. First we have Richelle Flanagan. Richelle is a CORU State registered dietician who has been a practicing dietician for 19 years. She is also a World Parkinson's Congress ambassador and committee member of the Dublin branch of the Parkinson's Association of Ireland. She is particularly passionate about the unmet needs of women with Parkinson's. She recently coauthored a paper on the unmet needs of women with PD.

She's also a co-founder of the women's Parkinson's project and co-founder of a startup, My Move Matters, a digital self-care companion to meet specific needs of women living with Parkinson's. We also have joining us Erin Presant. Erin is a board certified neurologist and fellowship trained movement disorder specialist with a certification in culinary medicine. Dr. Presant has experienced working in the academic environment as well as in private practice. Now having co-owned her own movement disorder practice, she has experienced in clinical trials as well and enjoys being a part of the research. Erin has founded the Medicine of Yum, I love that name, her new virtual culinary medicine endeavor. She's passionate about empowering her patients and feels that culinary medicine is the way to do that. Erin is also the co-author with Rachel Dolhun from the Michael J. Fox Foundation and the newest diet guide Brain Food: Eating Well if You Have Parkinson's (or Worry You Might Get It).

And finally we have Amber Fegter. Amber is an occupational therapist who received her bachelor's degree in health sciences and double minor in health and history from Bradley University. Her master's is in occupational therapy from the University of St. Augustine and she's a doctorate in occupational therapy also from the University of Augustine. She has special interest in neurologic conditions, low vision, lymphedema, and she holds certifications as a certified brain injury specialists and is an impact trained occupational therapist. She is also the occupational therapy practice resource at Brooks Rehab Hospital in Bethany Park.

Now let's get right into the meat of things right now, diet is important for everybody, but especially for people with Parkinson's and those who are at risk for developing it. Diet can help manage some symptoms. We aren't 100% sure yet, but it may slow the progression of Parkinson's disease and especially with what we have learned about the gut in recent years. It may also potentially prevent disease altogether for those at risk. Now, personally, I think nutrition was one of the hardest part for me to dial in. Challenges around finding what works for me in terms of medication and treatment. Exercise and mindset was tough enough, but nutrition was really the hardest for me to figure out from trying to understand how food interacts with medication to how my body is being field for physical activity, everything in between, plus the added challenges of finding something sustainable. Richelle, what are your experiences as a person with Parkinson's and diet?

Richelle Flanagan:

Yeah, well, it's kind of ironic that I'm a dietician and diagnosed with Parkinson's. I suppose when I was diagnosed, I actually picked it up when I was in my clinic with a patient who'd come back to see me and that's how I picked up my micrographia through the writing in the record card. But as a dietician, I always would be advising patients with cancer, diabetes, heart disease to look into the information to connect with your local Parkinson's group to get support. And what I noticed was there was lots of information with regard to exercise, but there was very little about diet. And when I researched into it myself, I realized that diet has a huge impact from beginning to end regardless of age and stage of Parkinson's. So there's a huge dearth of information and support for people at Parkinson's. So for me it's continuing on in terms of having a healthy diet.

For me personally, one of the core things was I had low blood pressure. So it was actually adjusting that I didn't realize low blood pressure was associated with Parkinson's in terms of timing of meds, very important. Keeping a regular bowel, I actually have celiac disease, so making sure that I get the nutrients that sometimes can be missing when you're on a gluten-free diet, that doesn't mean that people with Parkinson's have to be on a gluten-free diet. So what I would say is that there is so many elements of diet that are not been provided to people with Parkinson's that would definitely help moderate their symptoms and potentially slow progression.

Yeah, thank you. And I think there's something that you said is very important here is that the diet is going to be important for people of all ages no matter when they were diagnosed or what stage of Parkinson's they are living with and even for those who are at risk and may not be diagnosed with Parkinson's today. And the second thing is from both from both of our perspectives. And you just mentioned that it seems like that diet is something that's very difficult to figure out because there's not a lot of information out there. So hopefully we'll be able to shed a little bit of light on that today. Now when it comes to diets or what to eat, two of the most mentioned diets when it comes to Parkinson's is the Mediterranean diet and the MIND diet. Richelle, can you tell us how similar they are or how different they are?

Richelle Flanagan:

Yeah. So it's a bit of a mouthful, but the MIND diet is a Mediterranean dash Intervention for Neurodegenerative Delay diet. And basically the dash diet is the dietary approach to stop hypertension. So they kind of combine these two diets to improve brain health and Alzheimer's in particular. And then you've got the Mediterranean style diet and really the two of them are very similar. It's basically if you think of going on holidays to the likes of Greece or France or Spain, you'd have a lot of fruit and vegetables, you'd have a lot of seafood, whitefish, oily fish, and you would have a lot of olive oil. And in terms of fruits, you'd have fruits as well. When you're on holidays in France, you don't see loads of corner shops selling loads of sweets and chocolate and it's not something that's a mainstay of their diet.

But in terms of the core difference is that the mind diet tends to have more focus on the berries in terms of fruit. And interesting enough, there has been a research study that has shown that specifically berries may be associated with slowing Parkinson's. So that's in terms of, just have little sort of demo here, your blueberries, it'll be your strawberries, your blackberries, all the different sort of rich colored berries and taking them in a good couple of times a week and you can use frozen as well as fresh. That's no problem. So that is a big difference. Also, the other thing is in terms of MIND diet, they sort of advise to sort of steer away from butter, cheese and they have a focus on the olive oil as well. In terms of dairy, they don't kind of give guidelines so much in terms of the dairy in the MIND diet.

In the Mediterranean diet they would just say a moderate intake, but they don't sort of focus on you should cut out cheese and butter. So that'll be the difference between the two of them. It's quite subtle. What I would say is the research is quite intriguing. More recently, the papers I've read, the MIND diet is if you're sort of having a race, the mind is kind of leading the moment. And there was a paper that was done actually out of the UK research study that showed that actually women benefited more from the MIND diet then men did. And men seem to benefit a little bit more from Mediterranean.

So I think rather than getting too complex about it it's basically focusing in on the core healthy eating foods, which is your fruit and veg, your whole grains

which help to nourish the microbiome, the gut bacteria that you're mentioning. Then taking in the fruit and the berries that have the anti-inflammatory things that help against Parkinson's and the olive oil also that has benefit. And then there is a fat in the fish that also is potentially beneficial for people of Parkinson's. So a combination of those foods, whether it's the MIND diet or the Mediterranean is going to be beneficial for you and your Parkinson's, but also for other conditions you might have, which is quite common in Parkinson's, diabetes, heart disease, and cancer.

Jimmy Choi:

No, thank you for that. And what's in one very important point you brought up as I think you're just starting to bring into light some of these, how these are similar and some of how they're different. But one thing I think we should emphasize from what you just told us and I agree with you is that between men and women, it could be very different just because of how our bodies are. And it just can vary. What works for one person may not work for the other person.

Richelle Flanagan:

Absolutely. And you've got to take into account that younger people of Parkinson's are going to be maybe doing more exercise into training. So that's going to require different amounts of protein and carbohydrates and then you've got women in terms of whether they're premenopausal or postmenopausal is going to impact in terms of their dietary needs as well. So there are those subtle differences that we do need to take into account.

Jimmy Choi:

Yeah, absolutely. And whenever we talk about food and nutrition, people always think almost to the, well, "the obvious", which is it makes your body's stronger and better, but really everything starts up here in your brain. So Erin, can you tell us why diet is important when it comes to brain health?

Erin Presant:

Yeah, of course. So it's funny because for so long we've known how much diet impacts our cardiovascular health and things like diabetes. And it's just been really more recently that the idea that what you've put into your body can actually affect your brain health too. And of course if you really saw them think about it's kind of like, yeah, of course it would affect my brain and anything that we're eating can be good for our body or bad for our body or somewhere in between.

But diet really affects our brain by increasing inflammation, we think. It affects our gut microbiome, which there's a bunch of research going on right now about how that might affect our brain health as well. And I think that the Mediterranean, the mind diet, I think Richelle did a really great job of breaking them down. And I think that they both really highlight the need for these whole foods, less processed foods as those processed foods are what we really see contributing to this brain inflammation that's likely contributing to cognitive decline and neurodegenerative diseases like Parkinson's for instance. So just as exercise is important for your cardiovascular health and diabetes, but also your brain health food is as well.

Great, thank you. And we have really just started to scratch a surface here. So for the audience that is watching and listening, I want to plant a seed here as I think all of you out there listening and watching should ask yourselves this question as we move forward along to these topics. And the question is, how do you determine what is the best diet for you? Okay. And your initial answer to that for yourself might change as we go along through this entire webinar here. So panelists, if people are out there asking themselves that question, how do you determine what's the best diet for you? Do you have one tip that you can give to the audience as they start to think about this for themselves? Erin, I'll start with you.

Erin Presant:

Yeah. When I work with people, my thought is you got to do what you're going to be able to do. So if somebody tells you, you know, have to cut out all sugar and all animal based products to somebody who has a very American type of diet, they may be able to do that for a little bit of time, but they're not going to be able to sustain that. And so then that diet isn't helpful at all. And the way I've worked it and not my family too is make small changes, add things to your diet like vegetables and be less concerned about pulling things out and really restricting. And you'll see that slowly as you add these other components like vegetables and fruits and more whole grains, those other components kind of fall off without ever feeling like you're restricting yourself and having to be on this strict diet.

Jimmy Choi:

Thank you. Amber, how about you?

Amber Fegter:

I would have to say as well as a diet that's going to be easy enough for you to be able to replicate over time so that way you're able to follow it, but also some-

Over time so that way you're able to follow it. But also something being able to have those hopefully locally sourced products that are near you. So seasonal fruits and vegetables, especially adding that into your diet rather than having to only eat the frozen foods that might be available at the grocery store. And just experimenting and finding different ways that you enjoy being able to eat what it is that you find, whether it's steaming vegetables or cooking them in something. Finding new ways and just experimenting and having fun with the food that you're trying for the first time.

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Jimmy Choi:

Thank you. Richelle, do you have anything else to add?

Richelle Flanagan:

Yeah, I have two things, but I'm going to say one, I think what I find in terms of helping behavior change is actually having a look at what you're doing currently. So I always advise people to do a little food diary and do it over say five days, a weekend and three weekdays consecutively, because we all change our eating habits weekend to the week. So everyone's good during the week maybe and then they blow it all at the weekend.

So I think that's a bit like the bank balance. If you're not checking what's going in, what's going out, you can't really balance the books. So in terms of the same with diet. And the word diet I hate because people always think of weight loss, but it's actually the diet is the type of foods you eat. So what can be quite useful is to just do that and just watch what you do, observe what you normally eat. And also to put in your symptoms, your Parkinson's and see when do they tend to fluctuate in the day and do you notice any pattern, maybe put in some of your bowel symptoms, do you have constipation?

What things are going on? And then you can compare your diet to a healthy eating diet or to the Mediterranean style diet. Now there's the Eatwell plate in the States and it's based on healthy eating and trying to keep out the processed food. But then you can start looking back to the point of Amber and Erin and saying, oh, I noticed I don't actually eat fruit at all, or I don't eat any veg. And then you can start. And just pick maximum three things that you might say and then start with the low-hanging fruit, no pun intended in terms of the easy things to bring in. But I think by actually looking at what you're doing really helps you to make the changes.

Jimmy Choi:

Yeah, that's very good. I think some of the keys that are across the board is make it easy for yourself, make it sustainable, make it accessible. Add foods that you have easy access to and then of course make it repeatable so that you don't fall out of, if it's not repeatable, if it's difficult, you fall out of that pattern to try to change what you're trying to do with your diet.

And I'm just going to add one more, and this is a big one for me because initially when I started my own health change journey with living with Parkinson's, I was told to, just like Erin said, just cut out all the sugar and all that. But no, don't ever use food as a punishment. Don't think of eating a donut as, oh man, I got to go run three miles to burn that off. So I think that's for me from a personal perspective, I think that's something to think about as well.

Now thank you guys for all those. As we dive deeper, naturally the question comes up is what foods should we incorporate? I think that's a very natural progression into we're what we're discussing here. So Richelle, as a dietician, can you give us some tips on what and why certain foods should be incorporated?

Richelle Flanagan:

So I have a little demonstration here of foods. So in terms of whole grains, so getting in your whole grain foods, so it'll be your whole grain pastas, I don't know if you can see that. So basically what I would say to you is that if your plate is very white in terms of your foods and you look at it and it's looking very white, it's probably low in whole grains. So your whole grain pastas, your whole grain rices, your whole grain breads. And also trying different grains, things like, I don't know if you can see that quinoa, which is a really lovely grain to use, buckwheat, various different grains. And then the other thing is, going back to

the Mediterranean diet, a core part of it is your pulses. So things like your Haricot beans, your lentils, these are all good foods to eat.

And in terms of, you'll see here that I have a tin of pulses, you can use tinned. Ideally best if you can choose the organic, but at the end of the day it all comes down to budget. Obviously the best form is to steep your pulses overnight, but there's a bit more work involved with it. So in terms of whole grains, and really important because a lot of people Parkinson's suffer from, as I say, bowel, up to 60% have constipation, so it's really important to keep the bowel moving. So I'm just conscious you might want to ask the others. So I don't know whether you want to pass or I can do more.

Jimmy Choi:

And so we talked about what foods to incorporate are. Are there certain foods that we should avoid?

Richelle Flanagan:

Well, one of the big ones is, and it's not avoid, I think we really need to go back to your point of there's no good or bad diet. It's what's healthy and less healthy for you. So there's a spectrum of healthy to less healthy. And really the sugars are the ones to be mindful of. And one of the things, particularly in people of Parkinson's is because it affects dopamine, people tend to have a sort of, when they're going off, they want to pick themselves up and sugary foods have this tendency to maybe feel like they're picking up their dopamine. Fatigue is a big symptom. So we go to the sugary foods, try and boost us up. So I think it's important to look at if you have cravings for sugars, is to actually look, again, if you do a food diary, you can see your patterns.

Are you going off, are you getting tired? So then you can actually say, okay, I know what's happening. I'm going to actually have something different like mixed nuts and olives, for example, as a snack. Or you would drink something like a lime juice, which is kind of sweet but doesn't really go well with sweet sort of foods. So in terms that the sugars, they tend to have a kind of proinflammatory impact.

And also one of the key things is that they potentially are feeding the less healthy bacteria in the gut, which is higher in people with Parkinson's. So people with Parkinson's have to be really aware of the whole food cravings issue. We know there was one study, the showed that women with Parkinson's actually had a higher level of food addiction and tendency to binge eating than men with Parkinson's. And if you find that that is something that you're really having struggles with, you really need to get a referral to a dietician to really help you manage that. And not to be ashamed about it. It's a bit like impulse control disorders that people have, and basically food fits into that.

Jimmy Choi:

Yeah, thank you. And just as you're talking about that I myself, I think I fall into a little bit of that whenever those cravings hit. And that I do notice that it comes more so during off times later at night for myself. And I know I wear these shirts as a joke like power by junk food, but at some level this lies true for me.

Because I do, even for myself, I think I can do better from that perspective. And so I think that's very important for people to come out to the open and admit it to themselves first because it is tough. Especially when we're sitting in front of the television with three cookies in front of our... And that's from again, personal experience.

Richelle Flanagan:

And I think you've got to so take into account that people who don't have Parkinson's really struggle with reducing sugary foods. And we have a lack of dopamine, that's an extra barrier for us. So I think you're right, you have to be kind to yourself, but I think you need to get that help if you're struggling. And there are ways that you can bolster up. And a lot of people fear being hungry if they think they have to cut out. But when you bulk up on the really good foods, it's amazing the amount of people who realize that actually they're not as hungry as they thought they'd be. Especially men have a real fear of hunger.

Jimmy Choi:

And I can attest to that. And you're right, eating the right foods can definitely help curb that feeling of needing to eat. So over the years, I've talked to many people who have had success with diet and Parkinson's. I noticed that the only thing in common is that they're all different. Some obvious factors could be availability of foods in regions like we've already talked about, but what are some contributing factors? And I'm going to pose this question to Erin.

Erin Presant:

Contributing factors to the diet that somebody might choose?

Jimmy Choi:

Contributing factors to why everybody's different. Why?

Erin Presant:

I mean that's such a good point. I love that because when people hear Mediterranean diet, they think, oh, okay, I'll try the food from Italy or Greece or someplace else in the Mediterranean. But it doesn't necessarily mean you have to be eating that food. You can just incorporate the components of a Mediterranean diet, which are really eating a certain amount of vegetables and a certain amount of fruit and legumes and nuts. And all of these things if you actually look around the world from many different cultures, these types of foods are incorporated in many different cultures. So if your background is not from the Mediterranean and you like other flavors, that's completely okay. And I think that that's a big contributing factor to why some people don't even want to try the Mediterranean diet like, well, I don't like falafels, so I'm not going to, I don't want to eat it.

And it's really not about the Mediterranean food, it's about a type of eating where we're really eating more nutrient rich foods and reducing more the foods that we see in this Americanized type of diet. So when you're thinking about what kind of food you want to eat, make it your own, use your own spices, use the vegetables that are from the part of the world that you like. If you aren't so keen on bananas but you love papaya, great, do it, eat that. But you got to definitely eat the food that speaks to you, that is the healthier food for your body.

And that's a great point. I think that the bottom line is to make it your own. And at the end of the day it's about what you're taking in, and not necessarily the types of food you are eating to get what you need into your body.

So just for everybody to know that if you guys want to learn more about the specifics and learn more about the foundation's new diet guide, there's a link in the resource list available in this webinar and you guys can click on that link and get to the diet guide, which is, once again, it's called Brain Food Eating Well If You Have Parkinson's Or Worry That You Might Get It. And once again, Erin is a co-author on that along with the Fox Foundation's, Rachel Dolhun.

So the very next question that we always get is that, this is all great, we're all going to eat well and healthy, but how can eating well help me with my symptoms. So Erin, I'm going to turn to you on this one.

Erin Presant:

Okay. Yeah. And when I talk to people with Parkinson's, I have to recognize that just as Richelle mentioned with the sugar component, people with Parkinson's are dealing with so many other issues too going on in their bodies. So it's not just talking about reducing sugar. And that's hard enough for a person without Parkinson's, but when you're dealing with constipation or possibly low blood pressure or swallowing problems or smell loss and all these other things that are going on with your body, even depression and fatigue, it can be really hard to think seriously, now I have to do something with my food too.

So one of the, as Richelle mentioned, most people actually struggle with constipation, those people with Parkinson's. And there are a few things that you can do that can help. Certainly these aren't a miracle cure, but they can help. And of course drinking a lot of water. I think at least a lot of people that I work with definitely don't drink water or definitely don't feel like they want to drink water. So tend to go towards other drinks like maybe sugary drinks or caffeinated drinks.

And caffeine is fine. Actually, there have been a number of studies with brain health and things that suggest maybe caffeine is actually fine for brain health. So if you like your cup of coffee in the morning, go ahead and do that, but you also need to be drinking water because that's how our gut actually moves and will help with that constipation.

Eating more fiber. So if you think about what we're talking about with the Mediterranean mind diets, that fiber can come so much from those vegetables and fruit that you add to your diet. And you would be surprised at how much more fiber you'll end up eating when you start bringing those things in.

And then making smaller meals. So some people with Parkinson's may actually have a decreased appetite because of this lack of movement of their gut. And so kind of making smaller meals throughout the day rather than eating three big meals or what we talk about with eating, it can actually help with that

constipation. So you may be actually able to get in a little bit more fiber throughout the day. Of course, if you are still really struggling, getting a referral to a GI doctor or somebody can also help.

In general, we don't necessarily recommend taking probiotics unless its been suggested by a doctor that is treating you. And the prebiotics, which is really that fiber you get from those good fruits and vegetables are very, very important for our gut health. Another thing that people struggle with is low blood pressure, as Richelle mentioned. And this can become worse for some people as they move through the disease and later on in the disease.

Again here, the hydration is super important. If you really dislike plain water, you can drink some sparkling water. You can add just a little bit of fruit juice to plain water. Let's say you have an orange or a grapefruit. We don't want to necessarily drink a bunch of juice, but adding a little bit to water can be helpful so that you're not so bored with just plain water. This is one time where you'll hear a doctor say that you should add salt to your food if you're really struggling with that low blood pressure. Having something like salted nuts or something like that to snack on can be helpful to boost that blood pressure up. In this situation, you will want to limit alcohol.

Alcohol can cause that blood pressure to drop. In general, alcohol's always a topic that people ask about. It can be dangerous in Parkinson's in that you might already be struggling with gait or balance problems and alcohol can certainly make that worse, so you do want to be very careful. More and more, literature's coming out on the effects of alcohol on the brain. It's really all over the place in the literature. I'm going to just say limit your alcohol. We can probably do a whole webinar on alcohol and how it affects the brain and body. Then again, here you want to eat smaller meals so you're constantly putting something into your body and increasing that blood pressure over time rather than these huge bursts where you might get this rise in your blood pressure and then a quick drop.

I'm going to move to smell loss first because then I think Amber will have some great input on these swallowing problems or discussion about that. Smell loss can certainly make you to have appetite loss. This can actually come up to 20 years before you're diagnosed with Parkinson's disease. Smell loss makes your food seem bland. You can do things like adding spice. You want to try to not add salt. So use other spices besides salt. You can try spicy food or sour food and definitely using different textures of food. The quinoa is a great example that Richelle was talking about. It adds some texture to food. Or adding nuts on a salad or things like that can really make your food seem more appetizing. We eat with our eyes. If your food doesn't look great, then you probably won't want to eat it.

If you just have a plate of brown food, you're going to be like, "Ugh." Especially if you can't smell it, it's going to be even worse. So it does matter what you put

on your plate. It doesn't have to be like Michelin star looking, Pinterest perfect. Just make it look good for you. You don't need to post it on social media or anything, but make it exciting to your eyes. Another thing that people with Parkinson's can struggle with are maybe swallowing problems. This is going to be very specific to you and your disease. There may be things that you can do to help with your swallowing problems. You probably need to go ahead and get a swallowing evaluation to really learn what is the right way for you to be eating. Just saying, "Oh, if you have swallowing problems, you need to have a purée diet" is not necessarily the right thing and actually could be harmful to you.

So make sure that you are getting evaluated for that if you feel like maybe you're having some swallowing problems. In fact, sometimes we don't even know you're having swallowing problems, so a swallowing study is often a good thing to go ahead with as you're being evaluated by your doctor.

PART 2 OF 4 ENDS [00:32:04]

Jimmy Choi:

Thank you. Just really quickly on the topic of swallowing, Amber, I know we are going to cover some adaptive strategies here in the next few minutes, but just since we're on the topic of swallowing, are there some strategies that you think you can add into this current conversation here that can help those who are already wondering about swallowing?

Amber Fegter:

Yeah. Absolutely. One of the biggest things is that as people are aging in general, whether they have Parkinson's disease or not, they tend to maybe take the same size bites as what they did before. So making sure that you're cutting your food smaller, into smaller pieces, especially if you're eating meat, for instance, like chicken or fish. Taking those really smaller bites, taking the time to chew slowly, that's not only going to help you be able to taste the food that you're actually eating like what Erin was talking about with the loss of smell, but it's going to allow that extra saliva in your mouth to help moisten it so that way it goes down easier. Another thing that could be helpful is doing what we call a chin tuck. We normally have our chin and jaw forward. It's actually tucking it back. So while you're actually swallowing, it would be something as simple as that.

Another thing could be also alternating bites with whatever you're drinking. If you are eating something, take the bite, swallow it the whole way, and then take a sip of whatever it is that you're drinking. That way, it really helps to force the food down, but also keeps your mouth moist so that way, you can enjoy the next bite. Because having saliva is actually one of the best ways that we can actually taste our food. Having a dry mouth is going to make the taste not as good as what it could be. Another thing would be actually avoiding straws. Especially my patients that have Parkinson's disease, they love having straws because it makes it easier to manage cups depending on the weight of them. But find a cup size or glass or mug, whatever works best for you, having

something that you can manage even if it's full, so that way, you can avoid using straws.

Straws increase the risk of aspiration or it's something going down the wrong pipe, which is not good for anyone, much less somebody with Parkinson's that oftentimes has compromised respiratory function as well because it makes it harder to cough it back up. Along those same lines with the risk of aspiration or something going down the wrong pipe, like Erin was talking about, the journey for somebody with Parkinson's is entirely different. You have some people that never develop swallowing problems or some people that get them pretty quickly and easily recognizing them. Some things to look out for is that if you notice that you cough after you drink something especially, or if you cough when you're eating, that's probably a good sign that something is not right going on in the structures of your throat or it's not going down the right way.

Another thing to also be thinking about is that if you're having a conversation with someone, if you're having dinner with someone, after you take a bite of food or after you take a sip of something and swallow, if when you're talking, your voice sounds wet or gargly, that's a good sign that something is again not right and that you should talk to your physician to try to get a referral made for a swallowing evaluation. So that way, it keeps you safer in terms of your ultimate swallowing. Another thing to consider too is choosing foods that are softer just overall. If you really love carrots, for instance, you don't have to eat them raw. Steam them, cut them so they're smaller bites so that way you can actually get them down easier. Just removing the factor of what could be difficult for you makes life easier.

Jimmy Choi:

Thank you. As you were talking there, I was trying that tucking the chin back swallowing and it does make a difference. I had never even thought about that and I was never taught that before, so thank you for that. I learned something new today. And also,-

Amber Fegter:

Actually-

Jimmy Choi:

... with the straw, I would've never thought that a straw would be, I don't want to say negative, but it could bring a higher risk when it comes to using a straw. I never would've thought about that. We're looking at all of these different symptoms that people with Parkinson's have to deal with and we talked about in this entire section. One of the things that touches me the most is the loss of smell. I actually lost my sense of smell. Gee, I don't know. I can't even remember when was the last time I was able to smell, especially, I lost my senses off before COVID made it a cool thing. No, it's not really that cool. It sucks, but not being able to enjoy my food because of the lack of scent is terrible because I'm a food guy. I do all the cooking in the house. The biggest problem for me is that I've become the default go-to guy to clean up messes in the house when the kids or a dog gets sick.

But on the topic of smell loss, I just wanted to take one quick second here to call out that the Michael J. Fox Foundation has a landmark research study. We want to understand those who have Parkinson's and those who don't, we want to understand more why. Michael J. Fox Foundation's offering a smell study. We are offering a scratch-and-sniff test free to anyone ages 60 and up without Parkinson's in the United States and Canada. If you guys would like to participate in the study, please click on the link to the resource list and you'll find all the information where you can sign up and get your free smell test. It's very important as the more data we can get, the better information we have to get to some of the answers that we're all been looking for.

But back to the conversation here. Let's talk about simple things that you can do today that make changes. Then if we have time, some less simple changes, we can get into those too. People often ask me, for example, how do I optimize medications based on diet? Erin, can you talk about how diet can affect Parkinson's drugs and medication perhaps?

Erin Presant:

Yeah, definitely. One of the most common medications that people with Parkinson's are put on is Sinemet. It's also known as carbidopa/levodopa, a super long name. This is one of the medications where your food can interact with the medication. The protein of your food and the medication bind to the same receptor in your gut. So if you've just eaten a bunch of protein and then you take your medication, you'll not be absorbing that medication. Now there are about 10% of people with Parkinson's who are very, very sensitive to this interaction. I have had patients tell me, "If I have a teaspoon of peanut butter anywhere within two hours of my medication, I freeze. I can't move." You may notice, why didn't that dose of my medication work as well as it did before? It could be this protein interaction.

So depending on how many times a day you're needing to take your carbidopa/levodopa, you may have to adjust your meals around that. Sometimes, having a more protein loaded meal in the evening is something that people can do because then, if you're just going to bed, you may not need to be quite as mobile as during the day. If you're taking medication three times a day, just usually we say an hour before or an hour after your levodopa dose that you can have your meal. But this is going to be personal for each person and it is a little bit different. If you're on a dopamine agonist like Requip or ropinirole, those types of drugs, they don't actually require any special type of diet. You can have an impulse control disorder with those drugs, however, that may cause you to want to eat a bunch of sweets or alcohol or any of these other things, but that's a little bit of a different issue.

Drugs like an MAO-B inhibitor like selegiline, some people are put on these drugs and there is an interaction with something called tyramine. However, the tyramine interaction, you would probably need to be eating quite a bit of tyramine to see this interaction, but it is there. Tyramine is found in strong cheeses like blue cheese and really aged cheeses, home brewed beer or tap

beer, cured meat, which you should probably be staying away from anyway, and things like Marmite, which may not be super popular here in the United States, but other places, it's super popular. There are foods that are higher in tyramine that you may want to avoid or limit as much as you can.

Jimmy Choi:

I'm glad you mentioned Marmite, and we talked about smell earlier. That's a very pungent-

Erin Presant:

Oh, it is.

Jimmy Choi:

... food. I've had a chance to try that probably three or four years ago, and that was one of the first few times where I was able to get a hint of something, so I was glad for it. Again, like you said, it's an acquired taste. I didn't acquire it myself, but I was very happy to be able to grab a whiff or a scent of something. But going back to your point about how protein and medication, I myself have had that issue. For me, and again, this is a personal thing for me, I find it better to take your medicine and then take the protein. So take your medicine first, wait an hour, and then eat your protein or protein-rich meal. Then to Richelle's point, having that log about the food that you're eating and how it interacts with your medication and how you're feeling, it's also very important to help you identify whether or not protein is actually affecting your absorption of your medication.

Erin Presant:

And one thing about people sometimes say, "Oh, my medication makes me nauseated. I need to eat it with food" or things like that. That may be true. If you are taking your levodopa with food, try to make it less protein-rich food. You don't want to necessarily take it with a hamburger. Try to make it with a piece of toast or something like that, so the nausea is not as bad. Sorry, I forgot to include that.

Jimmy Choi:

No, and that's great because 10-ounce ribeye sounds pretty good with every dose of medication. Richelle, I just want to turn to you real quick. We probably should move on to the next topic here, but what are some helpful hints to healthier eating from your perspective?

Richelle Flanagan:

Well, I suppose when you were talking there about symptoms and management, I suppose just touching on [inaudible 00:47:44] say nausea, something that people need to think about is Parkinson's can slow the gut as well. It can slow the movement of food out of the stomach. You can get a thing called gastroparesis, which basically is a slowing of the stomach emptying.

So if you're getting nausea a lot, that's something that you need to talk to your neurologist about. Also, in terms of timing around your meds. So you'd often say after meal one to two hours. The reason that's kind of like a range is that if you're going to have a three-course meal, it's obviously going to have a lot more protein and potentially fats in it, which slow the emptying of the stomach. And what happens is the tablet gets, basically, it stays longer in the stomach and it

actually gets more broken down, so you have less of it that's going to be absorbed. So just be mindful of those kind of large meals. And if you're planning going out for an occasion, you might need to just be a little bit more planned around your medication. I think the other thing, just in terms of the point around the protein redistribution diet, which so when some people have lots of fluctuations during the day, we sometimes advise them and there has been some very good results from people going on those diets.

But just to say that you have to make sure you get the required protein amount in the day to keep your muscles strong and to stop you from losing weight. So not to attempt that kind of a diet on your own. Ideally you better do it under the council of your neurologist or a dietician to watch any weight loss. Because one of the worst things you can do for Parkinson's is lose a lot of weight such that you get underweight and that's not good for Parkinson's. So I would kind of keep an eye on your weight in terms of that as well.

And just lastly, in terms of timing of meds, and it's something that actually only just recently I've written a paper with Inducu Romanian and Carley Rusch, she's a dietician in the states who focus on Parkinson's and just looking at that protein interaction, there are some people who actually they might have some worsening of their symptoms when they separate their meds from their meals in terms of dyskinesia. So it's quite an individual thing and you need to talk to your neurologist. But again, if you track that and then you'll be able to have a better conversation with your neurologist, give them the information so they can actually define what's going on for you.

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Jimmy Choi:

Thank you. And that's a very important tip at the end is tracking everything and bringing that information to your visits. For obvious reasons, right, I myself, when I'm sitting in front of my MDS, I tend to forget things I want to ask, but if it's written down right in front of you, you won't forget to ask.

Richelle Flanagan:

Well, especially when you only have one hour a year with your neurologist.

Jimmy Choi:

Yes, absolutely true. So there are more of these healthy eating advice or more of these tips and tricks in that diet guide. Again, it's in that resource list. The fun fact guys, there are also some easy recipes as well that's included in that diet guide. So we're going to move on now. Amber, I know we talked a lot about food so far, and I want to get more into details on non-food related changes, right, relating to diet. So when it comes to things like meal prepping or shopping or just things around, not necessarily food itself, but related to eating and nutrition, but not necessarily food. Can you give us some advice on how to make or obtain healthier foods?

Amber Fegter:

Yeah, so one of the biggest thing is knowing where you live and what resources are available. So for instance, if you have mobility impairments, your gate is

fascinating or any of those types of things that make it difficult getting through a grocery store easily. There's a lot of grocery stores now that either are doing home delivery services that are for a very small cost or that actually would allow you to go to the store itself and they can put the food in the trunk. So it's just finding those options. But also if there's a local market that's close by that has locally sourced farmers products, that would be an easier option than having to go to the grocery store. But also finding out if those people would even be willing to make deliveries to your home. For instance, a lot, like especially where I live here in Florida, is we have a lot of farmer's markets where if you just ask the people that run those markets, they're more than willing to deliver the products to your home.

So just finding out really what's available to you. That could be as simple as a Google search, but also usually depending on different organizations that might be in the area such as Council on Aging, those different organizations like that, they should be able to provide you a list with what options might be in the area. So that kind of goes into ordering groceries in advance, so making it easier for yourself of planning meals for yourself. So being able to go with your recipe or something that you might want to try or say, I really like that food. Let me go through the groceries and see what I can find for myself to see what would go well together. Because going into a grocery store can be overwhelming. I myself don't like going into grocery stores. I order most of my groceries online because I end up buying too much and things that I don't actually need or I go in hungry and I see too many snacks that I want.

So the online shopping for me makes my life easier. So I have an app that I use and I go pick up my groceries. I can choose the time that I actually want to go pick it up. Usually I try to do a time where I'm not going to have to sit and wait in my car for too long. So there is lots of those types of options as well. One of them, for instance, it's Instacart. Instacart is with multiple grocery stores, but also depending on the area where you are, Kroger does do home deliveries after online ordering as well. So that kind of leads us into, once you actually have your groceries, how are you going to actually be able to prepare them? So we've talked a lot about the different types of changes that happen with Parkinson's. Each person is unique in what potentially they're facing with their Parkinson's disease, but there's a lot of adaptive equipment.

So there's adaptive equipment for meal prepping itself, such as adaptive cutting boards, using dice mats, using jar openers, having a Rocker Knife, things like that. But then there's actually adaptive equipment to help you actually just feed yourself such as weighted utensils, angled utensils, things like that. So it really just depends on each person and what they might possibly need. So it really comes down to figuring out what the barrier is for you. So especially if you have a family member that sees you, they can give you insight as well, especially if you're trying to feed yourself. Because a lot of times we don't want to admit that there's a problem or that something is difficult, especially when it's comes to something as simple as feeding ourself. But there's a lot of things out there.

Just talk to, there's a list of resources, but also if you're receiving therapy services, talk to your occupational therapist. They can help make recommendations for you, but also they can actually have you practice different things before you buy something.

Jimmy Choi:

Thank you, Amber. One thing that I like to add to that is, and you said it just right, asking for help is difficult, myself included. So I still do a lot of cooking at home. I actually I do most of the cooking at home. And if you have to use a knife, and I just want to provide this as an additional tip for everybody out there, if you have to use a knife, make sure it's sharp. Because having a sharp knife not only allows you to cut easier, if you do have an accident with it's a cleaner cut, it hurts less. And that sounds funny, but it's actually true. Having a sharp knife is actually a safety feature for that knife itself. But thank you very much for that.

We are running short on time, so I'd like to get to maybe one or two if we have time for questions because we get lots of questions. Hopefully we were able to address a lot of that during the topics that we've covered. But one of the questions that came up, and I'm going to Richelle I'm going to turn this one to you, is that what about pre and probiotics? Are those helpful, or and what are your thoughts on that?

Richelle Flanagan:

Okay. So yes, they're very helpful in terms of from the food sources. So in terms of your prebiotic foods, I just have a little demo here. So in terms of things like your nuts, things like leeks, your garlic, your onion, are all what we call prebiotic foods and they help to nourish the good bacteria so they have something to feed on. And then your probiotics actually include things like actually your yogurts with live bacteria in it. So what I would say about actually buying probiotics is that the evidence is not strong enough yet to advise people to take a specific probiotic strain. And that's because a lot of the standard probiotics that are on the shelf contain a probiotic that the people with Parkinson's have a lot of and they don't know by adding that in, whether it's making it worse or making it better. So the jury is still a bit out about that.

But suppose like Erin sort of mentioned, if you're working with a gastroenterologist who has specific knowledge around a probiotic and can sort of monitor you, that's fine, but I wouldn't be taking something off the shelf. I'd be using foods. And I think that's an important thing in terms a lot of people got out of the habit of actually cooking. And if you think of the base of a lot of cooking is your onion and your garlic, which are key prebiotic foods. So by buying processed foods, you're not always getting that. And back to the smell when you're cooking these kind of foods, they help to stimulate the smell and the saliva. So cooking more is actually going to be better for you and obviously using those adaptive tools to help you in whatever way you can and making it a family affair as well is important.

I like that. I like that, making it a family affair. We are coming up on our time now, and so I just want to real quickly to our panelists, thank you very much for joining us today. One last thought from anybody. Any of you guys can chime in if there's any additional, last thought you want to give our audience members.

Richelle Flanagan:

Well, I suppose one of the things I would say is in terms of people talk about vitamin C being very important for Parkinson's, but I think a vitamin C is vitamin connection. So actually connection and not being isolated. So actually meeting up with people to eat with your family and the cultural side is really important to people with Parkinson's. So having that connection really helps to stimulate your dopamines. So it's not just about the foods, it's about enjoying it with people would be a big message.

Jimmy Choi:

I love it. I love it. Erin, you had something?

Erin Presant:

I was just going to say, we don't have to make it so complicated. I think when you're first starting on this journey with Parkinson's, or even if you've had it for a long time, there's so much that's being thrown at you all the time and new symptoms and I can't do this or I feel like that. And so don't get overwhelmed by it all. Break it down into small, digestible, no pun intended, or maybe pun is intended steps that you can actually wrap your head around. Don't add more stress to your life and just give up. That's kind of what happens sometimes when we force or when we think, oh my gosh, I have to do this and this and this and this. Our brains just kind of say, okay, I'm done. I'm not doing anymore. Right. So keep it simple. And I love, love, love that comment by Richelle about connecting with other people over food. It's so important and we really have lost that in the last few years, especially, right, with the pandemic, but if we can get back to it, I'll be so, so good. Yeah.

Jimmy Choi:

Yeah. Keep it simple. I love it. Last thought, Amber.

Amber Fegter:

I would just have to say kind of rounding back to what Richelle was even mentioning is make eating and cooking something that's enjoyable for you. Enjoy that quality time with people. Find ways of trying new things that you enjoy. It might not be everybody's taste, but if you like it, then just try it. Enjoy that meal.

Jimmy Choi:

I love it. Thank you guys. All right, we are out of time ladies and gentlemen. Thank you again for being part of our community and for joining us today. One more thanks to our panelists for sharing your time and expertise. Thank you very much and have a great day everybody.

Speaker 1:

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