



Parkinson's Care Partner Training

Session 4: Parkinson's Nutrition

Davis Phinney Foundation

Note: This is not a flawless, word-for-word transcript, but it's close.

Polly Dawkins, MBA (Executive Director, Davis Phinney Foundation):

Hello, everybody, and welcome to session four of our Care Partner training program. I'm Polly Dawkins, and I work at the Davis Phinney Foundation. Today, we are very lucky to have Kristin Gustashaw joining us, and soon, she'll turn on her video and join us here. We have simply one hour today with Kristin, so we're going to just jump right into it. Today's topic is on nutrition and Parkinson's. So, to start off, Kristin, tell us about who you are, what your background is, and about the work that you do in the Parkinson's community.

Kristin Gustashaw, RD (Dietician, AIMS Clinic):

First of all, thank you guys so much for inviting me to share the hour with you all. Everybody's time is precious, so hopefully, everyone will leave here learning some things. I imagine many of you are not only watching, but probably doing other things in multitasking. So, thank you. A little bit about me. I've been at Rush for over 20 years, going on 23 and a half, and I've dedicated my entire nutrition career to aging and aging well. And along the way came a lot of disease states, and early on in my career, I was asked to give a presentation in the Parkinson's clinic. Now, our movement disorders clinic, we've even changed all of these names and centers of excellence and all of this. So, it's been an amazing journey working with all the different stages of Parkinson's and movement disorders and understanding the complexities.

And it's just fascinating how critical the nutrition component is for this disease as we age. And it's kind of cool because when I get to talk about nutrition, it usually is maybe focused on the patient or the client. But we all eat, right? So, you may have to be learning about a particular medication dose or how to, you know, take care of these types of things. But everybody around that person has a vested interest in their nutrition as well, hopefully. So, I've been doing that, and then I've worked with the Chicago department in aging. I do their menu analysis. I would go out for wellness presentations. Most of my career, again, is with aging. I'm in a neurologic, our ketogenic clinic now with adult ketogenic patients and epilepsy and other neurological functions. So, I could probably go on and on. I've had a lot of hats here in the kitchen, making our menu, planning for our own patients, and things like that on our dysphagia task force working about how we can make meals meet our patients' needs and swallow function and things like that.

Polly Dawkins:



Wonderful. Wow. You bring a lot of expertise to the table and to our care partner community here. And for all of you in the audience. We know that you are our care partners and that today's talk is really going to be focused on nutrition for the people that we're taking care of our person with Parkinson's. So, we're going to spend more time talking about nutrition for, for care for person with Parkinson's. But as you mentioned, Kristin, nutrition for care partners is also such an important equation or part of the equation. Because is it safe to say that the healthier a care partner is and the better nutrition they're getting, the better outcomes a person with Parkinson's is going to have?

Kristin Gustashaw:

Yes. It's not only safe to say, but it's even research-based. So, we find that not only the physical health of our care partners but their mental health so your whole person can have different outcomes of the person you're taking care of. And you know, I hope you don't mind, but really quick, I'm going to share a quick slide of this is one of my mantras, if you will, when it comes to patients. And I equate it to when you get on that airplane caregiver, six-year-old oxygen, oxygen mask first if you don't take care of yourself. It is not a selfless act. You will not be able to take care of the person that you want to protect or save or whatever's brought you to that table. So, this is how I often start most presentations, because, again, with the debilitating disease, the care part, there's always usually somebody else involved in the equation of nutrition. And whether they're here today as the journey progresses, and even again with aging, everybody takes different roles on what ends up going into somebody's mouth, whether it's the shopping or the cooking or, you know. Hence, it's very important to make sure that we keep that in mind the whole time.

Polly Dawkins:

Wonderful. Great. And as a reminder for our audience, many of the resources, slides, and topics we bring up today will be shared on our care partner hub for those of you in the future. So, to use our time well here, instead of starting with a bunch of questions, I think it would be important to start with sort of what are the biggest issues you found at the clinic when it comes to nutrition for people with Parkinson's.

Kristin Gustashaw:

So, I think probably one of the first things we ask about is unintentional weight loss. So, whether you are getting the call about coming into the clinic, you know, usually a nurse will kind of ask you a bunch of questions or when you're, you know, getting roomed and they say, you know, how's your height? How's your weight? I do recommend that everybody ask to be weighed, whether you want to know the number or not. Your weight and weight change tell us a lot about, you know, so many things, but even this disease and its progression. So, with this disease comes a bit of an insidious weight loss. You know, we almost call it a phantom loss, but we know bone loss and weight loss kind of are associated with this disease. So, if we can have a

really pretty good record of the weight trend, that can help us kind of determine how significant, you know, certain issues might be, or how that disease is maybe taking its course in your body versus somebody else's. So, when we look at unintentional weight loss, you know, it's 5% within a month, and it's 10% in six months. Now, depending on the size you are, that can be very obvious in apparent, or it can be very, you know, unassuming. You just don't even know. And most of our clothes are so elastic these days, it's very hard to give yourself a really good predictor of, you know, what your weight is shifting. And then there's something called sarcopenia, and that's just a natural aging progression of muscle loss.

Polly Dawkins:

Yeah. Okay.

Kristin Gustashaw:

So, it's not disease-related, but what happens is that as we get older, our muscles start to not thrive as much. We don't use them as much. We have hormones. I give whole presentations on how this sarcopenia affects our bodies, but then you layer on a disease, and the trajectory of that sarcopenia typically escalates. And what happens is your whole body might stay the same weight. So, you may be 130 pounds today; in 10 years, you might be 130 pounds. But a lot of people say, you know, my arms and my legs are getting thinner. And sometimes people turn into a bit of a marshmallow on toothpicks; look where the weight is the same. So, it's like every day you go to the doctor, and geriatricians are getting much better. The healthcare professions, now that this has kind of come to light over the last decade, it's like, whoa, we need to not just check that number, we need to start paying attention.

Like, what is this body looking like physically? So that unintentional weight loss could be happening without actually losing weight. So, you're losing the weight of the muscle. So, that's really critical. And what do you do to combat sarcopenia? What do you do to combat the weight loss with this disease? You have to eat a proper diet. So, what is that proper diet we need to focus on? It may be a little different for everybody. But we specifically call out the mind diet as kind of a nice little starting block and the mind diet. They started looking at it actually was research that came out of Rush, and it's an acronym that stands for the Mediterranean intervention for neurodegenerative delay. So, Mind. So, they looked at originally at, you know, Parkinson's and how we could reduce that risk. Well, since those original studies, they've kind of copied these, and they started looking at how it affects all these other neuro diseases.

And sure enough, it was beneficial and not a cause and effect, yet we're doing much more research, and we probably will end up getting cause and effect studies. But right now, it's people who eat these foods tend to be healthier, not only neurologically but vascularly. So, we look at those are the key components to try to get people with this unintentional weight loss to incorporate into their diet. But if you have, and this is very important for everyone to understand, especially care partners who are very diligent, maybe in their past histories of



caring for themselves or others, or their loved ones, if you have unintentional weight loss, you cannot eat too much of almost anything. So, we start to recommend adding in the olive oil, adding in avocado oil, full fat, everything, you know, really the floodgates get open because unless it's something like diabetes where your blood sugar is spiking, even then we look to medications to control that.

Because if you have this unintentional weight loss, you won't have any physical body to be treated if you can't stop the weight loss. So, then, that trumps everything. And we say, okay, this is the most important. And it's sometimes very hard for people to say, you can put butter on that or heavy cream, then they gasp. You know? But those are the types of things that you may hear if you meet with a dietician, them saying, so do not be afraid. And even with hypotension that becomes part of this disease, sometimes they're eating more salt than they ever thought. And that could be a component of their diet that seems so.

Polly Dawkins:

Yeah.

Kristin Gustashaw:

From what they may be.

Polly Dawkins:

Yeah. Because we've been taught growing up, we need to avoid salts and fats and avoid some of these things that you might be recommending.

Kristin Gustashaw:

Correct. And we still, if, you know, if you have a picky eater, we do not try to narrow anything. It's like, whatever. If they want French fries, give them French fries, you know, we have to stop the weight loss. But I did lead with avocado oil. Yeah. I did lead with olive oil. So, there are healthier fats and avocados themselves and nuts if you are not having chewing and swallowing issues.

Polly Dawkins:

Somebody just asked Stephanie just asked us. So, for somebody losing weight, it is a big bowl of ice cream every night. Okay.

Kristin Gustashaw:

And I absolutely love the ice cream. Yes. The first easiest answer is yes because ice cream also comes along with calcium. It comes along with protein, and it comes along with those extra

fats. I even like to doctor up the ice cream and say, would you like some heavy whipped cream on top? And if you don't have a chewing or swallowing issue, put some crushed nuts in there. So, really taking that ice cream and fortifying it as much as possible is a good idea. And one of the things that happens if you're losing weight often, you're not eating enough. And one of the reasons you're not eating enough is that you may be harder to chew and swallow. Appetite loss goes along with the disease, but it does with aging, too. Some people have to shift gears and say, I can no longer wait to be hungry. I have to eat because I know my body needs fuel. We even sometimes, in our clinics, put food and eating on the medication regimens. You got it. They just have to look at it as a job because people are often much more compelled to follow the medication regimen they're given, they're given, and they think the food is not as critical when the opposite is often the case. It's like if you don't get the food in, your medications are not going to be able to be utilized the same way in your body. So, you know, you need both.

Polly Dawkins:

And let's, can we just be very clear, Kristin, about this? Yes, it's okay to eat ice cream every single night. Because in some cases, that wouldn't be Okay. So, depending on the person's size, or

Kristin Gustashaw:

This is in the context of unintentional weight loss. Okay. So, if you are not gaining weight and you continue to lose weight, it is recommended if that's what you're going to eat, you know, I could give you another, we could again have another hour talk on other options. But if that ice cream is the one thing that you can successfully get that person to eat.

Then that's okay. And it's not going to be their entire needs. Right. Because ice cream doesn't have all the nutrients your body needs. But if you add in vegetables or fruits some other part of the day, for some people, it becomes a pre-made supplement. You know, we can make concoctions and all these recipes of our own natural supplements with, you know, pureed fruits, blended, frozen, but you could buy, sometimes people get most of their nutrition from something like boost very high calorie. It's, you know, 530 calories per container, 21 2, 22 grams of protein. And it's a fortified supplement with all these vitamins and minerals. So, then I say, well, if you're only going to be eating ice cream in the evening, you're still going to be nutrient-poor somewhere else. So, then I may have to; it's like a give and take. You can have the ice cream, but what else can we get so you can help meet these other needs?

Polly Dawkins:



Okay. So, really, just to clarify here, we're really talking about if somebody is wasting away unintentional weight loss and it's the only, ice cream is the only thing you can get them to eat, but there are choices that might be better than that.

Kristin Gustashaw:

Correct. And then for anybody, you know, again, if your weight is stable, if you're getting in all your other nutrients in the day, now that's very important. And to clarify, if you are getting a variety of foods in your diet and you want a small, like half a cup of ice cream every day and that's your treat, you know, most of us could incorporate that into a meal plan. What happens is, unfortunately, sometimes people will maintain their weight by enough calories.

So, if you eat enough calories, you can maybe hover around that. We'll just use that one 30 as the example. But if you don't give your body enough protein, no matter how many calories you get, your muscles will atrophy faster.

So, your muscles need protein. Now, it doesn't have to come from animals; it can come from beans, peas, and beans. It can come from all the animal meats, it can come from eggs, it can come from cheese, dairy. But if you don't get enough protein, your muscles don't have enough resources. So, they have to look within themselves and say, okay, I'm going to just chip a little bit away here because I didn't have enough protein today. So, you know where that protein comes from. Looks very different for a lot of people, but it must be there, or you will atrophy.

Polly Dawkins:

Super. We have; I know we have four other issues that we're going to go over today, and I want to make sure we give enough time, even though this topic of unintentional weight loss is critical and crucial. So, before we jump into each of those, tell us what the other four issues that you see over and over again, and then we'll go into each one a little bit more specifically.

Kristin Gustashaw:

Constipation, dehydration, and we talked about unintentional weight loss and chewing and swallowing. Great. So, dysphagia.

Polly Dawkins:

Great. So, let's dive into one of those next topics. I've seen quiet, quite a few comments already about swallowing. So, could we jump into chewing and swallowing issues next?

Kristin Gustashaw:

Yes. So, again, with normal aging, people are quite shocked. Normal aging does have a swallowing component to it. In fact, we all aspirate every day, no matter how old we are. Some



of our secretions just go down into our lungs in very minute amounts where it doesn't cause a problem. And our lungs are strong enough to absorb whatever bacteria might have got in there. You have these little microbursts of, of, you know, your body just compensates, but as you age, that can become a problem with normal aging. Then, with this disease, it's definitely becoming a component for many people, but not all. So, if it is a problem, it can become a very smoldering issue. You don't even notice, you know, everyone because we naturally do it. You might have a sip of water,

That went down the wrong pipe. I think we've all heard ourselves say that that's aspirating. We don't call it that, but you just aspirated if you've ever done such a thing. So, if that's, if you're a care partner, sometimes you maybe notice that it happened more often. If you're the individual with the problem, you may find, I feel like it's something's getting stuck here, or it took me twice as hard to swallow like these really hard swallows. Sometimes, it happens with pills first. For some people, it will only ever happen with pills. So, I'm just paying attention grossly to what it feels like to swallow. For some, it might look like it's difficult to swallow thin liquids like just regular water is a thin liquid. There's a whole nomenclature now called the IDSI, and it's the International Dysphasia Diet. And it breaks it down into different textures. This is why I would like to share a slide that I am going to,

Polly Dawkins:

While you're doing that, can you do can you define dysphasia for our audience?

Kristin Gustashaw:

So, it is defined as difficulty chewing or swallowing. Great.

Polly Dawkins:

Thank you.

Kristin Gustashaw:

Okay. Thank you. I'm so used to saying it.

Polly Dawkins:

Yeah.

Kristin Gustashaw:

Okay. So, I'm going to just share this really quickly. And this is a little intimidating to look at there, but this is, would-



Polly Dawkins:

Can you make that bigger for us? There we go.

Kristin Gustashaw:

Is it bigger now? Okay. So, this is all of the solid textures, and this is all the liquid textures, so if you're ever talking with a speech pathologist, I recommend everyone get a baseline swallow study if possible. Because that is just like your weight loss, if you can have, how's your swallow now? How's your swallow next year? You know, if you're starting to see some, any symptoms, you know, of course, if you don't feel anything, that's fine. But if you're starting even to see the mildest of, doing that more often, don't be afraid to ask the doctor, can I have a baseline swallow study? And the speech pathologist will give you some food to eat, and you swallow it, and then they assess how exactly you process that bite and that swallow. And then the disease, as it progresses, may affect somebody's swallow.

It's a muscular disease, right? It affects how your muscles move and work when the swallow and your GI are muscles. Some people could have a good Parkinson's day where the muscles that they feel and use like this are fabulous, but it's not a guarantee that the muscles in your swallow or your gut are going to have a great day the same day. So, it could have a good gut day and a bad movement day. So, they don't always go together. In an ideal world, when your medications are all working in harmony and everything's beautiful, it should work. But this is the diet, and this is what we talk about. So, this is a puree diet where everything looks like pudding. I think most people know what puree looks like. So, all the foods would puree, that's like the strictest diet.

But then these little pieces you might see minced, moist, so very soft where it would mash through a fork. And then, the minced moist is where each particle of the food is no bigger than the space between a fork. Okay. So, it's very specific. So, these are vetted, and there's a lot of research behind if you have the swallow study, which one of these things will help reduce your risk of aspiration for that chewing and swallowing. And as far as resources, this IDSI has a website, and there's a ton of videos where if you get to say, okay, I need a puree diet, it's going to show you exactly what that looks like. And it can, the period one's kind of an obvious one because it's, but even how much it hangs on a spoon is important. Okay. So, there's a lot of different things to consider. And we can keep talking, actually, if you don't mind, and I can just keep kind of showing. For some of the other ones, the minced moist is a little; it's very specific on this particle size. So, even in the hospitals, it's very hard to get the texture to that small, you know, you need the food processor to really break it down and mash your food into that bite-sized piece. Yeah. Okay.

Polly Dawkins:



Super. Thank you for that. Yeah. And we will share these slides in the resource area for folks, so you can watch them afterward. And so, they'll be there for you. Are there any other topics around chewing and swallowing?

Kristin Gustashaw:

So, one of the I know I kind of parceled this out a little bit of when we had kind of talked about what we were going to cover today, like kitchen devices and adaptive devices. So, if you are starting to have chewing and swallowing issues, there are a lot of different adaptive devices that you can use; this is more of the dexterity piece of maybe holding the spoon. So, they have spoons that have like a Velcro. So, they even have a spoon that, where it's mechanics, doesn't let the food tip off of it. So, it always leaves it parallel to the level ground. So, you can get it to your mouth. Then there are cups where there's a nosy cup where you don't have to tip your head back; you tip the cup, and it's cut out. There are straws where if you have a weak suck where you're trying to suck the fluid up where it has a no return valve, so you can, if you only have enough strength to get it halfway up the straw, that's where it stops.

You take a breath, and then you get it up the rest of the straw. So, just knowing to ask, again, we could talk forever, but knowing to ask about getting your swallow evaluated and then potentially working with them. The speech pathologist or occupational therapists are really good at determining the way your disease is affecting your abilities and where they can get purchased. I just happen to see that. So, you can look on the web for a million of them. The Swallowing Disorder Foundation is a great resource. But I can send these along with other resources.

Polly Dawkins:

Wonderful. We'll provide those to folks. I noticed a comment much earlier in our conversation about somebody who's having difficulties swallowing even water. What recommendations do you have for those swallowing difficulties?

Kristin Gustashaw:

So, water is tricky, and if you are struggling is a greater risk of dehydration. And I know that was another checkbox, so that'll be a good segue into dehydration. So, but for thin liquids, if you're struggling, you can buy more nectars, like even like juice nectar, but you may not want all that sugar and extra, you know, the juice, you may not like juice. So, they do make thick powders to thicken your liquid just slightly.

There's actually a ton of them on the market, and I'll share my screen here, I'm a very visual learner. So, you know, thicket, there's a resource, there's thicken up. They make pre-thickened liquid you can buy. Hormel has this thick and easy; then the resource is a thickened beverage.



So, you can buy them even in these kind of juices, thickened juices, or you can buy the thicket to just thicken it enough for your safety. But when you do, okay, go ahead.

Polly Dawkins:

I was just saying, Kristin just thickening will help with the thin-like liquid swallowing.

Kristin Gustashaw:

Yes. So, depending on, and definitely, if you are struggling with thin liquids and you haven't had a swallow study, you need to go see a speech pathologist. And one of the other reasons I remind people is that even if you have just slight changes, you notice even if they're not going to tell you to change your diet, the most powerful thing you don't want to overlook is there are exercises.

The speech pathologist can teach you to strengthen your swallowing. So, just like when you go to a trainer and they help you lift the muscles, you know, in your arms, the right way to pump your biceps and your triceps, they can teach you how to preserve your swallow and strengthen it. So, even if you feel like there's the slightest change, go get that workout. So, it's very critical.

Polly Dawkins:

Is there anything about using straws versus not using straws if you're having problems with swallowing?

Kristin Gustashaw:

So, for some people, straws are better. For some people, straws are very dangerous. So, when you take that swallow, and that's what the speech pathologist will kind of be able to assess, but even your own self, you can assess if I sip is it easier for me? Because we have extra secretion. Some people have a lot of extra saliva. And even getting the cup up to your mouth, you have drool coming out. But if you can keep your mouth puckered around a straw, sometimes they are better; have better luck keeping the saliva in their mouth.

It's a very individual response to that. But I'm definitely trialing each of these and the nosy cup. So, when you, if you have the anatomy of your swallow, you have your kind of your windpipe and your esophagus, and when you tip your head back, you open up the area to go right down your esophagus. But if you tuck your chin, you protect your airway better. So, when you drink a cup, you tip up, and you leave it open. And it's more dangerous if you're struggling in that area. So, using a straw helps keep your neck level, and it is safer than using a nosy cup. Again, you don't have to tip it backward. Right.

Polly Dawkins:



And when you, so-

Kristin Gustashaw:

You always want to, oh, go ahead.

Polly Dawkins:

You go first.

Kristin Gustashaw:

I was just going to say, so you really always want to like the gold standard where to see what the speech pathologist says is the safest way.

Polly Dawkins:

So always, and

Kristin Gustashaw:

Signs of somebody aspirating are a wet voice, a hoarse voice, a gurgling voice. A fever is definitely something never to ignore because that means that they like have pneumonia potentially. So, you want to be very cautious with that.

Polly Dawkins:

Super. Super. All right. So, we've talked a bit about unintentional, unintentional weight loss, chewing, and swelling. Did we actually talk about chewing, or was that more about the texture?

Kristin Gustashaw:

So, the chewing the textures, right? So, for some people, you know, I've worked with demisting people with no teeth who chew a steak. Okay. So, just because people have no teeth doesn't mean they necessarily can't chew.

But, in fact, for some people with partial dentures, if they do not fit right and they've had that unintentional weight loss, they actually hurt, and they can cause more problems than good. So, oral hygiene is critical, not only because if you aspirate and you have gunk kind of floating around in your mouth, it kind of, can grow bacteria, it can cause gingivitis, it can cause gum disease. And you want to remember your mouth is basically like a constant open wound. And it's always open to the environment. You know, if you have a cut on your hand, you're going to keep it very clean, put a band-aid on it so you don't get an infection. If you had your mouth is constantly open, but we are not always as careful about what's going in it and how you clean it.

People think if they have dentures, they take them out, and then they don't have to clean their oral cavity. Cleaning that oral cavity, even with no teeth, is critical. Then, cleaning the dentures themselves. So, the chewing part, that can be something that the textures are modified. And often it's not just the texture, but it's how moist the food is and maybe a cohesive bolus. And bolus means like the lump of food. Once you chew, can you get it to this little package that it's going to be easily swallowed. And again, another kind of tangible example is if you've ever had something in your mouth that's very dry and one piece breaks away. You know, you start coughing on that tiny little piece, having a more moist, cohesive pile like mashed potatoes you know, maybe corn and peas and carrots are safe if they're in mashed potatoes. But if you try to, if you don't have a good enough chew to break that down, you're going to have a couple of pieces kind of wandering away.

So those are the types of things you want to kind of pay attention to. And like peanut butter, peanut butter's an excellent protein. It's an excellent, you know, calories, it's a good one-stop shop for some things, but it's often too hard to manipulate around somebody's mouth. Sometimes we recommend adding a little olive oil or avocado oil to it to thin it or putting it into a smoothie or other preparations. So, where you can enjoy the nutrients and the flavor, but in a little thinner version.

Polly Dawkins:

Super.

Kristin Gustashaw:

And then I knew we were going to kind of segue into dehydration. Yeah. So, most of us, no matter the disease, humans, walk around dehydrated and die of a stroke where men are pretty much at any age and never hydrated enough. Women are pretty good during their mid-fifties, but then that's about it. So, we do a pretty good job, but then as we age, we all fall off meeting our requirements. A lot of it has to do with aging babies, potentially incontinence but also, our sense of thirst is never very robust. And it gets worse as we age, and it gets worse with this disease. So, just like keeping a record of your medications and the mealtimes, you may; your food might be okay, but getting that water, and I probably talk mostly about getting people to drink more.

And sometimes, it is because of the bathroom and the mobility issues. But you don't want to fix one problem and then cause a urinary tract infection. And remember, your water is necessary for your nutrients to get where they need to go. If you're dehydrated, it's like trying to ask your body to ice skate on concrete; you're just tearing up the blades. So, if you stay well hydrated, you get your nutrients where they need to go, the medications have a harder, easier time, your kidneys remain flushed, and they don't have as likely bacteria growth. It helps with constipation.



When people are constipated. And this disease is, I probably talk more about what's n not coming out of somebody than what's going in constipation becomes, in fact, sometimes even well documented a decade before they were even diagnosed with the disease.

Polly Dawkins:

Yeah. We hear that a lot.

Kristin Gustashaw:

We're seeing a lot of more gut symptoms before we ever really get a diagnosis. And because of that, in my world, people think, oh, I've always struggled with constipation. I just never had a good gut. And they're used to it and not necessarily doing much to see if they can help prevent it. And this disease, sometimes I've had a lot of people with bowel impactions hospitalized and having to have their bowels resected because of it. Like, it is a dangerous component of this disease. So, we know we, but growing up, you think, oh, constipation, eating, pooping, it's not a big deal. But for this disease, it becomes kind of the forefront of discussion and making sure you never go too long without a bowel movement. And many people I've ever heard say, oh, I've gone a week, I've gone two weeks. And that is dangerous. We try to say a rule of no more than three days on day three. If you haven't moved, you don't have a good enough intervention in place.

Polly Dawkins:

Yeah.

Kristin Gustashaw:

Things to keep in mind. Go ahead.

Polly Dawkins:

I was going to say, we spent a lot of time talking about constipation with Dr. Fleischer a few days ago, and we have that recording. Perfect. Perhaps you could come at that topic from a nutrition standpoint. Constipation, you said hydration.

Kristin Gustashaw:

So, number one is hydration,

Polly Dawkins:

Right?

Kristin Gustashaw:

So, you need to make sure you're, you're staying well hydrated. And, you know, people are like, does that mean eight glasses a day? And we often think about, like with medications kind of need their own hydration source. You know, if it says take with a full cup of water, that's because that medication to do its best job needs that much liquid. So, that's kind of above and beyond what you kind of need for just normal metabolic functioning. And what that looks like is very different depending on your size. This chart, I love this because for somebody who's only in you know, 60, 80 pounds and I do have some 80-pound people, that's three to five cups of water. But if you are up in the two hundreds, that could mean as much as 17 cups of water. So, that's a lot of water to be consuming.

You know, 16 cups are a gallon, so it's about a gallon a day. Most of us are around, you know, the eight, the eight-ounce cups are where everybody, you know, between here and here. It's like eight to 11 is often where people fall. But just to be mindful that you may need more than you need or than you think you need. So, when you're, I like to not go down a rabbit hole. So, if you are really struggling with constipation, give yourself a reality check of how much water you're drinking. how much fluid are you consuming on a regular basis because it may not cure your constipation, but it's definitely the safest way to help your constipation. And it's not only going to help your constipation, but also to help all your other metabolic functions. And then once you're well hydrated, that's kind of your baseline to say, okay, now how much more medicine now what other foods do I need to help combat this?

And when it comes to food, if you have severe constipation or your disease is continuing to progress, sometimes we have to stop and quite often the Metamucil or the fiber cons and all of the fiber sources because it actually can do more harm than good at some point. So, we really focus from my perspective, how much natural fibers can we get in from fruits and vegetables. And when we look at fruits and vegetables, our water content of our produce is so high, and this often will help with incontinence too. So, if you get a high-water content.

Polly Dawkins:

From food, so you can-

Kristin Gustashaw:

Get fiber, and you get all these micronutrients that are excellent for antioxidants and suppressing inflammation in your gut, in your body, in your brain. Kristin, we,

Polly Dawkins:

Your video, your audio went out for a few minutes. I hate to ask you to repeat that phrase. It just got muffled. Would you mind repeating that last little bit for us?



Kristin Gustashaw:

About the water and the food?

Polly Dawkins:

Yes.

Kristin Gustashaw:

Did you, okay. So, getting that much water from liquid can be a little laborious and difficult to do. But this is another reason why I recommend fruits and vegetables because this chart, as you can see our produce is almost over all over 90% water. And when you get water from your food, it's like a time released water for your kidneys. So, if you struggle with incontinence, it can really help meet your needs with hydration. It can help because of the fiber. And then it can also give you all these nice micronutrients, these antioxidants that helps to press inflammation that are good for your gut, that are good for your brain, your heart. So, it's kind of a one stop shop and you hit a lot of check boxes and you can even see eating, remember we talked about unintentional weight loss, eating in general gives you a lot of water.

So even pizza, I love this. I wish we could do like the assessment of Chicago pizzas and how much water each one has, but on an average it's almost 50% water, even pizza. So, if we eat food, we get some water. When you eat dry goods, like dried fruits, you'll get a great source of fiber, but it's not going to come along with the water. So, prunes are fabulous for constipation. With this disease comes kind of bone loss. I mentioned six prunes a day have been shown to help reduce the risk of osteoporosis. It helps, it's very good for bone health, and it takes about six, the equivalent, because there's loaded with all these micronutrients that help with bone formation and sustaining your bones. So, that can help your bones, it can help your constipation because they're prunes, they're a little dehydrated. So, they're not quite as dry as raisins, but they won't have as high of a water content. So, you might want to have your prunes with a nice glass of water or something.

Polly Dawkins:

And is there any formula that you could say that X number of things in the 90% water category equals an eight-ounce glass of water? Or is that too hard to figure out?

Kristin Gustashaw:

Well, you know, actually a lot, like a whole serving of most of these regular fruits is almost a half a cup of water.

Polly Dawkins:



Oh, okay.

Kristin Gustashaw:

So it is, it adds up quickly.

Polly Dawkins:

Right.

Kristin Gustashaw:

And so, then I like to say if you could get four to five servings of fruits and veggies a day, not, and at least half of your water, you know, as a base.

Polly Dawkins:

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Kristin Gustashaw:

Right. More is better. But if you're really somewhere who is like, I take three cups of water a day, or I only take water with my pills, the more you can up this, the better it'll be. But yeah, it tends to be like a half cup, quarter cup per serving of the produce.

Polly Dawkins:

Wonderful. We have a question that comes up often Kristin, which is about protein. And you were talking about our muscles needing protein and to stop from eating themselves or wasting away. But so many folks are trying to deal with protein and medication and the conflict there between the absorption of protein versus the absorption of meds. Can you give me a little help there?

Kristin Gustashaw:

Yes. So, when I first started working with people with Parkinson's almost 20 years ago, I was telling everybody, okay, this is the most important thing to get your carbidopa-levodopa to work. You've had to get protein out of your gut. While that is true for many people still, I have learned over the decades that there is a huge spectrum of sensitivity to that and so many different things that play a role. So, if you don't have constipation, your gut's working more efficiently, you may not have as big of a problem. Or even if your gut's working like that, your body may be more sensitive to that interaction than somebody else's. So, my blanket statement is do not just assume you have to eliminate it all away from your medication. As a rule of

thumb, the packaging usually says to take your medication, wait at least 30 minutes, and then eat your protein. For some, that's not enough.

Kristin Gustashaw:

For some, it's not even necessary for some people to eat their meal, and they go about their business. The reason why I'm so passionate about this is that, quite often, when people start taking their medications closer together, there aren't these gaps of time where you have this half hour, and then you wait two hours. So, if you take it, you wait a half hour, then if you've eaten, you should wait about two hours. Well, some people's guts are way slower than two hours, so they're going to need more time. And then it gets tricky because then they start avoiding food and then they fall into this unintentional weight loss category, or they skip their medication. So, people get all wrapped up in how important that is when they really should say, I know I have to be careful, so I'm going to try the half hour. I'm going to see if it makes a difference.

Kristin Gustashaw:

I may need an hour, but paying attention to that pattern is what's most important. And journaling, when does your medication kind of kick-off, or did it not kick in and looking and reflecting at your diet? So, food journaling is important, especially at the beginning of taking that medicine. And then, if you're feeling something's changing with your medicine because it's a progressive disease, you may actually need more medicine, or you may just need to adjust where your protein's coming from because it can get as intricate as the type of protein. Some people who eat plant-based proteins don't have a problem at that time. Some people have to avoid the protein altogether till, say, the evening. It's called a protein redistribution diet. I've only successfully met somebody; I'm sure there are people out there who we just haven't connected with. You take the medicine normally all day, and you only eat 10 grams of protein in total.

And for reference, an egg is seven. So, it's a very little amount of protein all day long. A piece of bread is usually three normal pieces. You eat all your food, and then you catch up on the protein in the evening. So, you have liked your medicines working all day, but it does come at a price because then you may not be able to get out of bed. So, for this one, man, it totally changed his life. It saved his life, as he says. But he wanted to go to a wedding one night, you know, he was planning a wedding, and it was okay, now I need to be on during the evening. So, about two or three weeks before, we shifted it all, and then he was on during it worked during the day, and then he was on at night, and then he shifted it back. But those are very rare cases. Yeah.

Polly Dawkins:



So, really, the takeaway from that is, as you said, a food journal is to track your symptoms, track your medication, track your food intake, and your responses to all of that.

Kristin Gustashaw:

Correct. Because people often just over-restrict, and they maybe change the wrong thing, and we want to keep nutrition as enjoyable and as nutritious as possible. Yeah.

Polly Dawkins:

We've got a couple of, I'm going to get into a couple of questions from the audience, but an important thing that our care partners find is that they're in charge of nutrition and for their person. Any suggestions for care partners, what they can do, what we can do to help on the nutrition front, or what to do if our person with Parkinson's is resistant to the nutritional behaviors that will help best?

Kristin Gustashaw:

So, one of the things that it often comes down to if we're talking about nutrition is like how I often talk about how to get five bytes to count for 25, right? So, if you are struggling with what to get somebody to eat every bite and it's just very difficult, or it takes somebody way too long, then fortifying what you're offering can really be helpful. So, this slide here is just another example of these where this is from the senior dietician. She's a colleague that I used to work with quite often, but milk powders condensed milk right now. This bean calorie is out of supply right now, but bean protein, so there's modular, you know, and this little one-and-a-half-ounce container has 330 calories and seven grams of protein in a one-and-a-half ounce shot glass, if you will.

So, incorporating things like this into food and looking up shakes and smoothies that people might enjoy, I feel like there's a huge market on sweet things, and some people like, I'm done with the sweet. So, then also look at savory things, if they like oatmeal, and how to put like more savory flavors into the oatmeal. Like, you know, using the olive oil and butter and leaving out the sour the granolas and the nuts and the fruits, I'm trying to keep it savory or soups. Soups are an excellent way if you can make a soup and add a couple of tablespoons of olive oil to their portion; speaking about the care partner, maybe the care partner doesn't need more nutrients or more calories, but you make one big pot of soup, and maybe you turn their portion into a cream-based soup with heavy cream and maybe more ground chicken in it and an extra scoop of olive oil. So, taking what they'll eat, even if it's very simple, and seeing how you can add more calories to it is often what I talk about a lot.

Polly Dawkins:

Great. On the other side of the spectrum, we see, and David mentions in the comments, an issue with sugar cravings. We see that a lot in our community here. And what can a person, what can a care partner do to help with a person with Parkinson's who has these sugar cravings and is gaining weight and only wants to eat cereal and cookies and cakes and coke?

Kristin Gustashaw:

So, at, if you can, you know, and that is a tricky piece. If you can't switch at least half of the things to, you know, I'm not a huge fan of artificial sweeteners, but then just like with the unintentional weight loss, the weight gain is going to be very hard, and that's going to be more of a problem than an artificial sweeten. So, if they can, but sometimes you can't just cold Turkey it and say, okay, you're getting Diet Coke and not Coke. But caffeine's not great, and that's dehydrating. So, maybe they're getting sprites, and you can do diet Sprites or half, half as much. So, if somebody's drinking a lot of pop and half of a p sugar-free and half be regular, not giving one and the other, but can you slowly, you know, give a quarter of it being the diet and you know, not to be, you know, you'd be very transparent to the patient or your, your loved one but pouring in a little bit because you know, in one 12 ounce can, that's just empty calories, right?

One hundred sixty empty calories of pop, and you may have somebody drinking two liters a day or two liters a day. So, trying to switch out any, you know, or a whole sleeve of cookies, can we rotate in some other sweeteners, or will they do like a sugar-free jello and maybe with whip topping, you know, still making it entice but trying to do, kind of finding that middle ground. Because it is, it can be tricky, and you know, depending on, you know, it's hard just to say, well, I'm not going to buy it. That doesn't necessarily work, either. Yeah. So, finding the opposite spectrum of how can I get the emptiest calories or the least number of calories with the biggest amount of volume and sugar-free candies and things are, are sometimes the alternative you have to go with sometimes getting people to eat like sugar-free suckers if their swallows okay. Because it kind of keeps their mouth busy for a while, and you want the sugar-free because you don't want the tooth decay and all the other things we talked about. You have good oral healthcare, but sometimes you try a little, at least, to pepper it in. Yeah. And avoiding altogether human nature does not feed into that well. So, trying to find some compromise, you'll usually be more successful than saying you're not getting any because it just will make that craving rage.

Polly Dawkins:

One of our movement disorder neurologists who's been on our webinars before Kristin has mentioned that those sugar-free candies or suckers can also help with constipation, but too, too much of it can have the opposite effect.

Kristin Gustashaw:



So, he is probably, he or she is referring to like the sorbitol. So, there's like, there's sugar alcohols and sometimes, and that can help move your bowels a little bit. But it can also help with, you know, if people have dry mouth a lot of times saliva's the issue, but getting people to swallow their secretions and things, sometimes those sugar-free candies help too. Great.

Polly Dawkins:

There are so many, so many questions. I think we could speak for another hour, and we're going to put links up and resources for everybody as we're starting to close the session. I will ask you a couple of really quick ones. We talked about avoiding artificial sweeteners. So, somebody asked about aspartame. Is that something we should avoid?

Kristin Gustashaw:

So, I feel like none of them are, you know, necessarily; I mean, they're still allowed on the marketplace, right? We know they're just, there's so much more research that it's just kind of tricks our body, whether it's insulin, whether it's our gut bacteria. There are so many reasons to say the natural is better, right? But as I said, if you have somebody who's gaining incessant weight, if you have incessant weight, your medications have a hard time if you have excess fat in your body. So, it's a balancing act. So, when people ask, is aspartame okay? Or, you know, Splenda, all of the green pack, I was like the green, the blue, the stevia is probably the one that's the most natural right now. So, I would go with something like that or monk fruit. But again, none of it in excess.

Polly Dawkins:

Kristin, thank you for your passion for this community, for working so hard in this community, and sharing it with us. It's a gift for all of us, so thank you.

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