



Transcript

Welcome and Introductions

Stephanie Paul

[Slide 1] Welcome everyone and thank you so much for joining us today. **[Slide 2]** My name is Stephanie Paul, and I am the Vice President of Development and Marketing for the American Parkinson Disease Association or APDA for short.

I am pleased to welcome you to this telephone and Web education program designed for people with Parkinson's disease (PD), care partners, family members, and healthcare providers. We are pleased to have Lisa Sommers, who is the Clinical Director, Center for Language, Speech, and Hearing and Clinical Assistant Professor, Department of Communication Disorders at the University of Massachusetts in Amherst and Dr. Stacey Zawacki, who is Director of the Sargent Choice Nutrition Center and Clinical Assistant Professor at Boston University in Boston, Massachusetts today sharing their thoughts to help you live well every day. Thank you for sharing your time and expertise with us.

I would like to thank Acorda and Lundbeck for funding this important program and acknowledge their continued appreciation for the critical need to provide educational programs like this one to people impacted by Parkinson's disease.

Before we begin, I would like to invite Leslie Chambers, President and CEO of APDA to say a few words.

Leslie A. Chambers

[Slide 3] Thank you, Stephanie. As many of you may already know, APDA is the largest grassroots network dedicated to fighting Parkinson's disease. Every day we work tirelessly to provide support, education, and research that will help everyone impacted by Parkinson's disease live life to the fullest.

Founded in 1961, APDA has raised and invested more than \$170 million to provide outstanding patient services and educational programs, elevate public awareness about the disease, and we have funded research designed to unlock the mysteries of Parkinson's and ultimately put an end to this disease.

Through our nationwide network of chapters and information and referral centers, as well as our National Research Grant Program and Centers for Advanced Research, we strive to assist the more than 1 million Americans living with Parkinson's to improve the quality of life as they battle this chronic neurodegenerative disorder. Last year alone, we sponsored over 1,700 support groups which served more than 74,000 people with Parkinson's disease, as well as family members and care partners; we provided over 750 exercise groups which are designed to improve Parkinson's symptoms and the overall health for the participants in these groups; and we have offered dozens of educational symposia across the country on how to live well while coping with PD. And these programs have been attended by more than 5,000 people across the country. It's programs like these, as well as



today's webinar, that truly distinguish APDA as a powerful resource providing support, education, and information to the entire community as we strive to live well every day.

Stephanie Paul

[Slide 4] Thank you, Leslie. We're ready to get started with our presentations. After the presentations, we will open up the program for questions from both telephone and Web participants. We encourage everyone on the line to complete the evaluation after the program because your feedback is instrumental in helping us plan for future educational offerings, including teleconferences like this one and other programs.

It is now my pleasure to introduce Lisa Sommers.



Presentation

Lisa Sommers, MA, CCS-SLP

[Slide 5] Hello, I'd like to thank the APDA for the opportunity to talk with you today about the importance of communication, cognition, and swallowing as they relate to Parkinson's disease. These skills are critically important to the general well-being and quality of life of people with PD but are often misunderstood or ignored. I'm coming to you from the University of Massachusetts, Amherst, in the Department of Communication Disorders where I work with graduate students and speech language pathology and audiology. I really enjoy teaching students the specialty skills that are needed to work in this very challenging clinical area of practice.

In this talk I'd like to provide you with an overall of the **[Slide 6]** communication and **[Slide 7]** cognitive challenges associated with PD, followed by a discussion of some treatments and helpful everyday suggestions to minimize problematic symptoms and maximize communicative and cognitive abilities. **[Slide 8]** I will also review swallowing changes that can be present in PD, along with evidence-based ways to evaluate and treat these issues. I'll discuss comments and suggestions for safety and enjoyment at meals. And, finally, I hope that you'll be motivated to connect with professionals that have a wellness approach to managing your PD.

[Slide 9] The overlapping areas between these three: clinical expertise, approaches that are evidence-based treatments, and a consideration and appreciation for the individual needs and values of a patient are all important. So, professionals who work with you need to have good technical skills, but we professionals achieve the best outcomes for our patients by focusing on the whole person and what makes them unique.

We have to individualize each and every evidence-based treatment with a focus on early detection and treatment of symptoms. In order to do this, you need to know the signs and symptoms to report; and that's what this webinar is all about.

[Slide 10] So let's start with communication. One underappreciated fact is that communication involves so much more than words. As you can see, only a small portion of our communication is actually the words we say. People often are aware that PD impacts speech. But, actually, PD impacts communication in every section represented in this pie chart. So let's talk now about how PD impacts the whole person and how they communicate.

[Slide 11] About 90% of people with PD will experience changes in communication, and those changes can be really very subtle and can occur, actually, quite early in the disease process. Tremor, bradykinesia, reduced amplitude of movement, and rigidity can affect the structures and movements involved in breath support, voice production, speed and accuracy of articulation, and inflection in connected speech. Additionally, people with PD often have changes in the nonverbal aspects of communication, such as reduced facial expression and fewer gestures. So when you combine all of that with reduced volume of the voice and lack of inflection in the voice, a lot of times the intent and the mental state of the person with PD is often misperceived.



And these changes aren't always recognized by the person with PD as there seems to be a sensory disconnect between the effort that they feel they're using to communicate and their actual volume and clarity of their speech. People also tend to talk less and less over time. A lot of family members tell me that they feel like the person in their family with Parkinson's stops initiating conversation so much or doesn't take as many conversational turns. Many people with PD report that these changes are more detrimental to their quality of life than anything else they experience with PD. And I found in my own clinical practice that when I'm working with people who are still working, they often have significant issues that crop up around their communication skills in the workplace, particularly people who are in sales or who are managing other people who lead meetings or do significant public speaking. And sometimes the first symptom is a decrease of facial expression or a monotone soft voice, causing people to be misperceived as disinterested or even depressed.

[Slide 12] So let's talk a little bit more about the specific symptoms of speech and voice problems. The most common symptom is reduced volume of the voice. People often describe their voice as becoming weak or quiet. Speech clarity and precision may also deteriorate as the voice softens. The voice may also sound hoarse, breathy, or harsh. In connected speech, the voice is often monotone with reduced stress and intonation overall. Many people who used to enjoy singing in the past will note that they feel like they have a reduced pitch range in their voice. They often can't hit the high or low notes in the music any longer; and, unfortunately, a lot of people decide to quit their choir or stop singing all together.

Rate of speech can be highly variable. Sometimes it slows down excessively while other times it increases and the person seems to stutter or stumble over sounds, words, or phrases. And the changes can occur so gradually that a lot of times even caregivers and even physicians don't recognize it's a problem until the person has actually become quite impaired. And this is, of course, complicated by the fact that people often fluctuate.

Medications that help other motor functions in the body have not been shown to be effective with the speech, voice, or swallowing changes associated with PD. And speech and voice symptoms are often made worse when a person with Parkinson's is asked to speak and do something else at the same time, like thinking of the words they want in a conversation or talking when they're walking.

[Slide 13] In terms of treatments, LSVT LOUD® has been well-researched and is considered the gold standard for treatment of the communication deficits associated with PD. It involves intensive retraining of the voice, with a focus on increasing the volume of the voice and retraining the brain to recalibrate what is the correct amount of effort needed to achieve a normal volume voice. People often experience improvements in not only voice but also the clarity of the speech, inflection in their voice, and improved facial expression. The website that I have here for you thoroughly describes the benefits for those that are not familiar with it, as well as the years of research that support the use of this approach.

The SpeechVive™ is also a research device that's used to increase speaking volume. The SpeechVive is worn in one ear, in a fashion similar to a behind-the-ear hearing aid. The device plays background noise in one ear when the person wearing the device is speaking; and then the noise



turns off when the person is not speaking, so it doesn't interfere with their ability to listen to their communication partner. And the SpeechVive taps into a normal reflex that many of us have called the Lombard effect which causes us to automatically raise our speaking volume when we're speaking in a noisy environment.

Now when there are cognitive or psychiatric challenges, there may need to be different modifications used, such as a pacing board in therapy or even alternative means of communication in the case of unintelligible speech that doesn't respond to other therapy approaches. But, in general, speech and voice treatments have at their core the need for the patient to expend more effort when speaking. And, of course, just as physical exercise is required, intense effort and then a continued exercise. Speech and voice games are needed to be maintained with a home exercise program. When the exercise regime is abandoned, and if the person stops speaking louder, patients usually experience significant detraining effects, meaning they go back to their pretreatment status.

But for many people with PD, it's really critical, and I really want to hit this point home, to remember that the best way to maintain the gains in treatment is to put yourself in social situations that are enjoyable to you, that give you meaning, that force you to get out of the house and be socially engaged, and using your voice and speech in conversations with others about things that you enjoy and you're really genuinely interested in. Therapy can help you return your voice to a normal volume, but the best therapy of all is using your communication skills in the real world.

[Slide 14] One other meaningful way to help maintain gains in therapy can be singing. So, singing is an increasingly popular way for people with PD to use their voices in an effortful, meaningful, and rewarding way. Small scale studies reveal some promising results—speech intelligibility and volume may improve, as well as respiratory support and quality of life. But more research is still needed.

Based on the evidence thus far, singing should not be used as a substitute for individualized speech services but rather as a complementary activity, especially for carryover of the louder healthy voice quality achieved by working in skilled speech therapy.

PD singing groups are now in many communities, and really they do greatly benefit from the collaboration of professionals with knowledge of how PD affects respiration and voice and cognition in order to choose music and instruct choir members in proper technique that will maximize the benefits of singing.

[Slide 15] So, I'm going to move on and talk a little bit about cognition. Cognitive changes do happen in Parkinson's disease at some point and tend to be progressive, but there's a lot of variability from person to person. I have found that this is something, when it comes up with the patients that I see, it can be very frustrating and have a lot of emotional consequences for people. I often find that this is an area of a lot of fear that people carry around with them and don't really want to talk about. You can see here the most common areas of cognition that are impacted. It's really important to treat issues such as depression or anxiety because those can also have a significant impact on cognition, and those are things that can respond to treatment.



And then I think it's really important to not ignore the impact that hearing loss can have on cognition. This is something that a lot of research is coming out about right now, and it's important to see an audiologist if you suspect even mild changes in your hearing. And be open to treatment because this can really have a significant impact on your cognitive functioning and your quality of life.

And then, of course, you all know the connection between physical exercise and cognition, and I think it's really important to see physical exercise as a part of a program of cognitive stimulation. Make sure to see a physical therapist as soon as you're diagnosed, and periodically and regularly to ensure you're doing the right things and are safe in what you're choosing.

In terms of evaluation and treatment, it's really important to discuss any changes that you're seeing with your movement disorder specialist. That doctor may recommend a neuropsychological assessment, and then often short-term, function-oriented speech language pathology services are very helpful, especially with a focus on compensatory strategy training.

[Slide 16] The last area that we're going to talk about today in my part of the webinar is dysphagia. I wanted to make you familiar with that term because that's a medical term for a swallowing problem.

And dysphagia can affect someone with Parkinson's at almost every stage of the swallow. So, there's an oral stage of the swallow, a pharyngeal stage, and an esophageal stage of the swallow. And it's not always correlated with the severity of Parkinson's that someone may have. It can impact people even at very mild stages of Parkinson's disease.

And these changes occur because of decreased force of movement, decreased range of motion, slowness of movement of the muscles, and a decreased ability to adapt to changes in volume and consistency of foods and liquids, as well as changes in reflexes that are involved in swallowing and airway protection.

And dysphagia can lead to real health consequences for people with PD such as weight loss and, of course, a decreased quality of life due to having unpleasant changes made in the diet. And then also with aspiration pneumonia, which is definitely linked to morbidity in people with PD.

And, obviously, there's a big connection between quality of life and swallowing, and there's really a link here with people socially isolating themselves if they do have dysphagia. Food's a very social activity. People like to eat with friends, family, coworkers; and this can be really impacted if people begin to withdraw because they're embarrassed about drooling or slowed eating or swallowing difficulties, fear of choking in front of other people, and even struggles with getting food from the plate to the mouth due to tremor or decreased coordination.

[Slide 17] This slide is for you to use as a reference so that you know what kinds of symptoms to be watching for and to report to your physician.

[Slide 18] And in terms of evaluating and treating this, it's very important to be watching for very early signs of problems; and your physician can write an order for dysphagia evaluation and treatment. The



first step is also what's called a bedside evaluation of the swallow, followed by a more in-depth and objective instrumental assessment that is often recommended.

The gold standard for Parkinson's disease is called a Modified Barium Swallow Study (MBSS), and there's really a lot of value in doing an MBSS early in order to have a baseline assessment. There can be very subtle changes that may not be problematic but are observable to a speech pathologist, and there may be real value in doing targeted exercises that address these vulnerabilities.

In terms of treatment, the overriding principles for treatment, just like with voice, are an intense period of treatment with lots of repetitions of exercises, a lot of physical effort. With this approach, I've had patients have excellent outcomes in swallowing therapy. LSVT LOUD is sometimes used also to address some of the specific swallowing issues that can arise, especially with things like elevation of the larynx. And, in addition, there are compensatory strategies and changes in posture and positioning that can be helpful, as well as looking at on/off periods for people.

[Slide 19] In terms of some guidelines and some common sense measures that I think are really helpful, I'd like to just highlight a couple of areas. In terms of positioning, it's really important for you to make sure that you're very comfortable, sitting in a comfortable chair, everything is within reach, and you're not having to work hard physically. And in that way, you can make sure that you're having to do just the work of swallowing and not holding yourself upright. If you're having difficulty with that, it's a really good idea to consult with an occupational therapist.

In terms of soft, moist foods, it's also helpful sometimes for people to have gravies or sauces on the side with meals, and I get a lot of questions about taking pills. I find that a lot of people try to take handfuls of pills, and I really do recommend taking pills one at a time. I know that people have a lot of pills that they have to take, but it seems to be an area of a lot of problems for people, especially large pills. And sometimes with large pills, it's helpful to put them one pill at a time in a spoonful of something smooth like pudding or applesauce. Follow that with a couple of swallows without anything in your mouth and then a sip of cold liquid. And, of course, do not crush pills without the approval of your physician.

So, I know this has been a lot of information in a short period of time, but I hope it's been helpful for you; and I look forward to taking your questions at the end of the presentation. And I'll turn it back over to Stephanie now.

Stephanie Paul

Thank you, Lisa. This has been a very informative presentation today. It is now my pleasure to introduce Dr. Stacey Zawacki.



Presentation

Stacey A. Zawacki, DrPH, RD

[Slide 20] Hello everyone, this is Stacey Zawacki. I would like to thank the APDA for the invitation to speak today. It's an honor for me to have this opportunity to connect with all of the participants to talk about nutrition and living well every day.

Nutrition plays an essential role in health promotion and the management of many chronic diseases. Parkinson's disease is no exception. **[Slide 21]** Here's an outline of the nutrition themes I will focus on today. Healthy eating goals for people with Parkinson's include adequate calories for a healthy body weight. Body weight changes are common in Parkinson's disease. People may experience weight loss prior to clinical diagnosis, followed by an increase in body weight during early treatment. As Parkinson's disease progresses, unplanned weight loss is associated with increased energy expenditure due to involuntary muscle movement and excessive muscle tone.

A balance of macronutrients, and macro meaning the big nutrients that provide calories, is important because of their varying effect on stomach-emptying time and the bioavailability of levodopa. The macronutrients are protein, carbohydrate, and fat.

A variety of foods from each food group is recommended to ensure adequate micronutrients, micro, meaning the small nutrients that don't give us calories, but provide essential nutrients like vitamins and minerals and protective substances like antioxidants and phyto or plant chemicals.

Lastly, constipation, loss of appetite, delayed gastric emptying, and medication interactions present challenges for people with Parkinson's. The goal of nutrition therapy is to counteract these nutrition challenges with targeted dietary changes.

Lisa included a set of helpful guidelines in an earlier slide, including small meals throughout the day; soft, moist foods that are easier to chew; and alternating small bites of food with sips of liquid. **[Slide 22]** Regarding unplanned weight loss, minor adjustments, ranging from 100 to 400 extra calories per day are often effective and can be accomplished with these changes. If you are considering a nutritional supplement, you'll notice that most products on the market are designed for consumers looking for extra protein. This is not a goal for people with Parkinson's. Low protein, high calorie supplements designed for people with chronic kidney disease contain a better carbohydrate-to-protein ratio.

[Slide 23] The primary role of carbohydrates is energy for activity. In addition, the brain is normally totally dependent on carbohydrates. Foods and beverages that are mostly carbohydrates have the fastest stomach emptying time compared to foods that are higher in protein or fat. This is helpful to know if you have delayed gastric emptying time. Fruits are 100% carbohydrate and are great for in-between meal snacks. Starches like breads, rice, pasta, and potatoes, as well as beans, peas, and lentils, contain mostly carbohydrate with small amounts of protein. Nonstarchy vegetables, the colorful vegetables, contain a balance of carbohydrate and protein.



You'll see fiber and added sugars listed separately on food labels under total carbohydrate. We'll talk more about fiber in a few minutes.

[Slide 24] Protein is a building block of cells and a big buzz word in the food marketplace, so people are often concerned that they're not getting enough. In fact, there are so many food sources of protein that people don't think of, like the grains and vegetables I just mentioned, and portion sizes are often so generous that most people consume more than they need. We will look at this in more detail in a moment. It is also helpful to know that protein is more satiating than carbohydrate or fat, and so it is often recommended to help people manage hunger when dieting. This is why it is so prominently featured as an ingredient in low-calorie products. For people with Parkinson's disease, where lack of appetite is a problem, such products are not helpful.

[Slide 25] Fat is a major source of energy and aids in the absorption of fat-soluble vitamins A, D, E, and K. Fat prolongs stomach emptying time, and so high-fat meals may exacerbate delayed gastric emptying. It is recommended to focus on heart healthy sources of fat like olive, canola, and peanut oils, nuts, nut butters, avocados, olives, and baked or broiled fish.

[Slide 26] When dietary intake of nutrients from food is compared to recommended levels, almost all Americans fall short. This is because most Americans do not eat the recommended amounts of health-promoting fruits, vegetables, whole grains, fish, beans, and milk or dairy alternative products that are good sources of calcium and vitamin D. Researchers continue to study the relationship between B vitamin intake, blood levels, and risk of Parkinson's disease. But, in general, the association between single nutrients and the risk of, and more importantly, neurological features of Parkinson's disease is controversial and needs to be clarified. This makes sense because foods are complex sources of multiple nutrients and sometimes countless co-nutrients. It is no wonder that it is difficult to determine if one or more are more important than the others.

[Slide 27] With that in mind, this slide lists food sources of several nutrients. You may notice a theme here. With the exception of fish – fruits, vegetables, nuts, seeds, beans, fish, and whole grains are all plants. Plants make substances that we can't make, and so it is essential that we eat them. In addition to vitamins, minerals, and fiber, plants contain neuroprotective substances, antioxidants, and beneficial phytochemicals.

[Slide 28] Bone health is a concern for people with Parkinson's. Enriched rice milk and almond milk are lower in protein and healthy alternatives for calcium and vitamin D. Vitamin D is challenging because there are limited food sources, and most people are not exposed to adequate sunlight to make it in their skin for many months during the year—because the light is not direct enough for many months of the year or we're wearing protective sunscreen and clothing or just being inside. It's recommended that you have your vitamin D levels tested to determine if therapeutic vitamin D supplements are indicated.

[Slide 29] A multivitamin and mineral is generally recommended but is not a substitute for healthy eating. Choose one that is age and sex appropriate to account for varying nutrient needs at different life stages. Vitamin deficiencies, like vitamin D or vitamin B12, should be confirmed by blood test and treated under your medical doctor's supervision. You may see supplements, including herbal



supplements or all natural supplements, that claim to help with certain health conditions or make promises like brain or memory support or increased energy. These are not recommended. Their ingredients may interfere with medications or worsen other conditions. It is very important to let your healthcare team know about any supplements that you are considering.

[Slide 30] Constipation is the most common GI symptom reported by people with Parkinson's. Nerve damage reduces muscle contraction needed to move food through the digestive system. Medications also play a role. Taste changes may increase the desire for sweets and replace higher fiber intake over time, but low fiber intake is common in the general population as well.

Recommendations for fiber are based on energy needs. Men are larger and require a higher calorie intake to maintain their weight. This is why the recommendation for men is 38 grams of fiber per day compared to the recommendation for women of 25 grams per day. The average American adult consumes only 15 grams of fiber. Water intake in people with Parkinson's is often inadequate for fiber to be effective. In fact, in the presence of inadequate water intake, high fiber negatively affects stool consistency and bowel habits. It is helpful to consume six to eight cups of fluid per day. Recent studies have also examined the relationship between the gut microbiome and constipation. Preliminary studies have shown improvement in constipation symptoms with fermented milk products that contains probiotics like kefir taken at breakfast time while maintaining or increasing fluid intake throughout the day.

[Slide 31] This table is designed to show the fiber related to recommended intake of fruits, vegetables, whole grains, and plant-based proteins like beans and nuts. The first column includes the type of food and the standard serving size. The second column shows the recommended number of servings per day. Looking at whole grains, you'll see that a standard serving size equals one slice of bread or one-half cup of cooked grains like rice or pasta. A meal may include more than one standard serving. For example, a sandwich at lunch with two slices of whole grain bread would count as two of the four recommended servings. A one cup serving of brown rice at dinner would count as the other two.

The third column shows the approximate fiber content per serving, multiplying the number of servings for a food group by the approximate fiber content equals the fiber contribution from that food group for the day. Looking, again, at whole grains, four standard servings at approximately 2 grams of fiber per serving equals 8 grams of fiber from whole grains for the day.

You can see that over the course of a day, eating the recommended number of servings from each food group adds up to 38 grams of fiber, and yet, the average American gets 15 grams per day. These foods would also provide protective vitamins, minerals, antioxidants, and phytochemicals that many people are missing.

[Slide 32] This slide leaves the number of servings column blank so that you can estimate your fiber intake. Take your time and come back to this slide to fill in the number of servings that you eat from each food group and multiply that number by the approximate fiber content per serving listed. Add up your results for the day and compare it to the recommended intake.



[Slide 33] We've already talked about the different stomach emptying times associated with macronutrients. Carbohydrate is the fastest, fat is the slowest, and protein is in between. Levodopa must travel through the stomach before it is absorbed. If it is taken with food, it will not be absorbed until the food leaves the stomach. Therefore, it is recommended that it be taken at least 30 minutes before eating. Heartburn, or acid reflux, and delayed medication effects may be signs of delayed gastric emptying. If you have delayed gastric emptying, you may be advised to wait 60 minutes to provide more time for your medication to leave your stomach.

In addition to increased fiber and beneficial nutrients, small plant-based meals and snacks may improve gastric emptying time because of their higher carbohydrate to protein ratio.

The results of a large observational study in Italy, published this year, looked at dietary habits of people with Parkinson's disease and their association with neurological features. In that study, protein intake was shown to influence levodopa therapy and related motor fluctuations. **[Slide 34]** Protein competes with levodopa for absorption and transport through the blood-brain barrier. Excessive protein intake was associated with higher levodopa dosage requirements. Higher levodopa requirements were also associated with constipation.

If you are experiencing moderate motor fluctuations, you may benefit from reducing protein intake by substituting plant sources for some of the animal sources in your diet and spreading your protein intake evenly throughout the day.

If you experience marked motor fluctuations, a protein redistribution diet that restricts protein at breakfast and lunch with catchup protein at your evening meal to meet daily protein requirements may be beneficial. A registered dietician can help with protein planning and redistribution to meet your daily nutrition requirements.

So, how do you know if you'd benefit from reducing your protein intake? **[Slide 35]** Let's take a look at protein requirements. Earlier, I mentioned that protein is a building block of body cells. The [recommended] daily requirement or RDA for protein is based on bodyweight because the more you weigh, the more cells you have that require protein each day. The formula is 0.36 grams per pound of bodyweight. This translates into 81 grams for a 225-pound person. As you can see, the requirement is less for people maintaining a lower bodyweight.

How do you know how much protein you're consuming? **[Slide 36]** Let's start by taking a look at meat, fish, and poultry. These meats contribute 7 grams of protein per ounce, but we rarely eat only 1 ounce of meat. A 3-ounce serving, is the size of a deck of cards. That equals 21 grams of protein. It is not uncommon to see an 8-ounce, which would be 56 grams of protein, or even greater serving size of meat. Think about a restaurant where a 6-ounce beef tenderloin is considered a petite filet, 42 grams of protein. A 12-ounce sirloin, 84 grams of protein, is the norm. Looking back at the protein requirements for a whole day, it is easy to see how typical meat portions contribute to excessive protein intake.



On the other hand, plant sources of protein, like beans or lentils, contain approximately 8 grams of protein per half cup serving. They also contain carbohydrate in the form of fiber for a more favorable carbohydrate to protein ratio.

[Slide 37] Dairy products and eggs are also sources of protein. An 8-ounce serving of dairy milk and soy milk contribute approximately 8 grams per cup. I mention soy milk because in a recent study, people had changed from dairy milk to soy milk thinking it was less in protein, but it's actually the almond milk and the rice milk that contribute similar amounts of calcium and vitamin D with only 1 or 2 grams of protein per 8-ounce serving.

Greek yogurt is popular today, but it is a more concentrated form of yogurt contributing approximately twice as much protein as regular yogurt. A one-ounce slice of cheese is similar to a glass of milk, but it is easy to eat several ounces of cheese if you're enjoying a snack of say cheese and crackers. Eggs are also a source of protein contributing 7 grams per large egg.

Of course, many people do consider meat and dairy products when they're thinking of food sources of protein. What they often overlook is the fact that typical intake of grains and vegetables meet a third or more of their daily requirement for protein. A registered dietitian can help you estimate your protein intake compared to your needs and help you modify your meal plan to meet your nutrition needs. This will help you optimize your levodopa dosage.

[Slide 38] In this slide, Lisa Sommers has provided several helpful dysphagia diet resources.

We hope that we have given you some helpful information today about some of the symptoms that can have a significant impact on your wellness and quality of life. And, hopefully, you have some tools and ideas of how to manage those proactively.

I would like to give Lisa Sommers full credit for these final suggestions: **[Slide 39]** pursue educational offerings in detecting and mitigating the symptoms of Parkinson's, both motor and nonmotor. Learn about early signs and evidence-based treatments and familiarize yourself with the terminology associated with these symptoms.

Track your changes. Consider a journal or daily log for jotting down concerns and notice changes. Look for patterns and context when symptoms are present or more noticeable.

Report even milder subtle changes to your physician and treating therapist and know what to ask for in terms of services. Self-advocacy is a building block for wellness.

Choose professionals that you feel comfortable working with at various times over the course of the disease. Do they keep up on the new treatments in their fields? Do they individualize your treatments? Do they educate you and make you feel empowered to ask questions and advocate for yourself? Form your team before you are in crisis. That way you can focus on making good decisions with advice and help from people who already know you.



Combat social isolation. Be vigilant and self-aware. When you feel yourself backing out of things that you used to enjoy, this is the signal that you may need help learning strategies or changing something in the situation so that you can continue to participate and enjoy things that give you meaning. Work with your wellness team of professionals, friends, and family to problem solve for communication, cognitive, mood, nutrition, and swallowing problems that may be preventing you from fully engaging with others.

Thank you so much for your time, and we hope that this has been helpful for you.



Question & Answer

Stephanie Paul

Stacey, thank you for this very helpful presentation today.

[Slide 40] It is now time for the question and answer session. I would like to remind all of you that we have hundreds of people on the phone and on the Web. To benefit everybody, please keep your questions general in nature, and our faculty will provide an answer general in nature.

We'd like to start our questions today, and this question is for Lisa, and it's coming from Steven in Maryland. And the question is, "My cognition, especially in word finding, seems to have decreased in the last three years since I've had deep brain stimulation. Is this usual?"

Lisa Sommers, MA, CCS-SLP

Well, I think that this can be something that happens even without deep brain stimulation to people, so it's kind of a difficult question to answer definitively. But I do think that word finding is a very, very typical complaint that people have, and it's very frustrating for people. It's very helpful to sometimes work with a speech language pathologist on learning some strategies to help you with word retrieval, and I think that it is something that the more you isolate yourself as well and withdraw from conversations, the less you're actually practicing that very active part of cognition that you need to do in real time in real situations. And so, I really encourage people to come up with other ways of letting people know I might have some trouble thinking of what I want to say, but stick with me because I really want to participate in this conversation.

And so, the more you withdraw, the more you're probably going to have a decline in those skills. So, if it's something that's so problematic that you really feel like you want to withdraw from conversing with others, I think that's the time to consult with a professional about it.

Stephanie Paul

Thank you, Lisa. The next question is for Stacey. This comes from Ralene. And the question is, "My spouse is taking pramipexole and has experienced about a 30-pound weight gain and cravings. What strategies would you suggest to deal with these medication side effects?"

Stacey A. Zawacki, DrPH, RD

So with weight gain, which can be very common especially early in treatment, the recommendations for healthy eating can actually be quite helpful in helping to moderate calorie intake. Fruits and vegetables can be very filling, and so they're very nutritious. They contain fiber, which is helpful with constipation and other symptoms, but they also can be very filling and, as part of a meal, can help us to feel full and satisfied while we're eating our meal. And so, making sure that meals are eaten throughout the day and that they're balanced, that they contain fruit and vegetable, a source of protein and whole grain, carbohydrate, if possible, is going to be helpful.



Stephanie Paul

Okay, thank you. I believe we have one question right now from a caller. If we could take that question, please.

Operator

Our question comes from Rod calling from Washington. Please state your question.

Barbara

Yes, actually, this is Barbara. I'm Rod's partner. And Rod eats up to three avocados a day, and I heard that avocados were a no-no, so I wanted to make sure I understood that correctly.

Stacey A. Zawacki, DrPH, RD

Well, avocados are not a no-no. Avocados are a very nutritious fruit and they also contain heart healthy oil. A lot of people use them as a heart healthy fat, but they're actually a nutritious fruit as well. Three a day is probably going to mean that he's filling up on avocados and may not benefit from the variety of other fruits, and also, vegetables that it's beneficial to eat. One of the core dietary goals in healthy eating is variety and that's because each of the different, colorful fruits and vegetables and whole grains and nuts and seeds contain an array of beneficial but different nutrients. To get the benefit of as many of those as possible, it's good to eat a variety of foods from each food group. Avocado is a healthy choice, but three a day is probably more than he needs, and it would be helpful to work in a variety of other fruits.

Barbara

Okay, thank you.

Stephanie Paul

Thank you, Stacey. Okay, we have another question for Lisa, and this comes from Virginia in California. And the question is when and how often to see a speech therapist?"

Lisa Sommers, MA, CCS-SLP

Oh, that is a great question. I think that it's a great idea to consider seeing a speech-language pathologist (SLP) early after diagnosis, just as you would with a physical therapist. I think getting a baseline evaluation is a great idea because you get a lot of information and education provided to you. You might even end up doing a course of therapy and be given some exercises to help to maintain those skills. We make a lot of different recommendations of specific kinds of activities that people can engage in. And I think that at different times in the disease you can look at this webinar and see that there are a lot of different signs and symptoms that you can kind of be watching out for.



I think the biggest key that I would like to get across to people is that it's extremely important to identify things early before they become a very significant problem and talk to your physician about things early on so that when you do end up seeing a speech pathologist, you're not having let it go for so long that it's a very, very severe problem so that you have so much farther to work back from. And I will say from my own clinical practice, it's really heartbreaking sometimes to work with people who have really been dealing with symptoms for years and years thinking that there was nothing that they could do about it and hearing family members say, "We had no idea that speech therapists did anything with people with Parkinson's." And there's still a lot that you can do with someone who's quite impaired, but it is so much better to deal with things proactively early on. That's really why I'm excited to do the webinar and be able to get that message across to people.

Stephanie Paul

Thank you, Lisa. That is really an important message. So, let's take another question. This one is for Stacey, and this comes from Linda in Virginia. And the question is, "Can you speak to fiber as related to constipation versus easier stomach emptying?"

Stacey A. Zawacki, DrPH, RD

Yes. So fiber, what we know from recent studies, is that people with Parkinson's disease do not take in the recommended amounts of fiber, and that's common in the general population as well. They also fall short of recommendations for fluid intake. So, foods that contain fiber are generally plants and not only are they good sources of fiber, which is helpful with constipation, but also the carbohydrate has the fastest stomach emptying time of all the macronutrients. And so, for delayed gastric emptying, it can also be a strategy that is beneficial. We do recommend looking at your intake of fruits and vegetables and whole grains and plant sources of protein that contain fiber like beans and nuts and comparing that to the recommendation to see if you would benefit from increasing your intake. And that's why I, in the webinar, included the table, one, to show an example of how recommended intakes for a man would add up to the 38 grams of fiber, and a woman would be able to meet her recommendation of 25 grams with even less food, and then to leave a blank table for you to fill in with the foods that you eat each day so that you can estimate your own fiber intake.

Stephanie Paul

Terrific, thank you, Stacey. We have another question for Lisa, and this comes from Lynn in Virginia. And this question is, "Please describe what a pacing board is."

Lisa Sommers, MA, CCS-SLP

Oh sure, that's a great question. A pacing board can look like a lot of different things, actually. It might be a paper with the alphabet on it in front of the person. That way people can pace themselves. To be able to slow down their rate of speech, they might point to the first letter that occurs in every sentence that they're trying to say. It sometimes is a paper with different colored blocks on it where they're putting their finger on each block as they're moving from word to word to be able to slow their pace a little bit more. It often helps to regulate the rate of speech that the person is talking at.



And I've worked with people where we've needed to, because they had so much difficulty with their rate of speech and their intelligibility, I would perhaps use LSVT with them, but I'd also incorporate a pacing board in the session so that, not only was their volume greater, they were also kind of slowing down their rate of speech a little bit if they were really having a lot of that palilalia.

Stephanie Paul

Terrific. Thank you, Lisa. Now we have another question. This comes from Carol in North Carolina. And the question is, "What is the difference between a modified barium swallow study and a barium swallow study?"

Lisa Sommers, MA, CCS-SLP

The difference between the two comes up a lot, and sometimes people even get sent for the wrong one for whatever purpose they're trying to accomplish. I'm going to start with a barium swallow. So, a barium swallow looks at the full functioning of the esophagus. It looks at the esophagus down and how things are getting from the esophagus into the stomach. In that test, you have to drink a large volume of liquid barium. Sometimes people with Parkinson's disease do indeed need a barium swallow because they are having esophageal problems, and the management of those problems would be more of a medical kind of management as opposed to a modified barium swallow, which is also a very common test that would be recommended for someone who's having swallowing problems because of their Parkinson's disease. That test looks at a different part of the swallow. So, that starts at the mouth and it looks at what's happening in the mouth and the throat and then the top of the esophagus. And in that test, a speech pathologist and a radiologist are present together in the test doing the test together as opposed to barium swallow a speech pathologist is not there.

And in the MBS, the modified barium swallow, they mix barium in with various foods and they drink barium of different thicknesses. The speech pathologists will try different postures or strategies to see if that changes the safety of the swallow or the timing or the coordination of the swallow. And then that helps us as therapists identify what's the underlying problem here, and then we can target that underlying problem with specific exercises. And so it's a very, very powerful tool that we have to target treatment with people, and it's really the gold standard for Parkinson's disease.

Stephanie Paul

Thank you, Lisa, for taking that. Stacey, here is a question for you. Jay in Indiana is asking, "Is there any connection between food/nutrition and increased dyskinesia?"

Stacey A. Zawacki, DrPH, RD

Well, we did talk about the effect of protein intake on levodopa requirements. So because protein and levodopa compete for absorption, if the diet contains high levels of protein, there can be a higher requirement for levodopa, and that can lead to the dyskinesia. And so the changes that I recommended today in moderating your protein intake, spreading it out throughout the day, including



some plant sources of protein, and looking at the portion sizes of some of the meat and poultry choices can be beneficial in helping to optimize that levodopa dosage.

Stephanie Paul

Terrific. Thank you, Stacey. We have time for one more question, and this question is for Lisa. This comes from Terry in Washington. And the question is, "What is the connection between PD and hearing loss?"

Lisa Sommers, MA, CCS-SLP

Well, I think the connection is merely that as all of us get older, as the population ages, people have hearing losses from the aging process. I think as a sort of related but not the same kind of issue as, there's still a lot about perception, auditory perception particularly, in Parkinson's disease that we still don't understand. And so I think there's really a need for a lot more studies in that area.

But just in terms of hearing loss with the general population as the population ages, untreated hearing loss is a big area of research now in terms of the impact on cognition. I think just from a general point of view just as people with Parkinson's often are older, with a certain segment of that Parkinson's population, that that's something that we really need to be paying attention to as a potential treatable area. We need to make sure that we're getting patients connected with audiologists and getting evaluations done; and people are getting treatment for their hearing losses because that really can have an impact on their cognitive functioning as well.

Stephanie Paul

Terrific. Thank you, Lisa, for that.



Closing Remarks

Stephanie Paul

[Slide 41] I want to thank everyone for participating in today's telephone and Web education program. I do apologize that we weren't able to get to all of the wonderful questions. But if you do have a question and would like to speak with someone in our Scientific and Medical Affairs Department, **[Slide 42]** I encourage you to visit our website or call 1-800-223-2732, and you can ask your questions there.

I want to thank Lisa Sommers and Dr. Stacy Zawacki for their presentations and also thank our APDA President and CEO, Leslie Chambers, for joining us. I also want to emphasize to everyone on the phone that we really do appreciate your feedback and comments and want to make sure that you complete the Program Evaluation Form.

As part of today's programming, APDA is excited to provide a new tool called the Healthcare Communication Graph that is now available on our website at apdaparkinson.org and is also available to you in the Resources tab on your screen. This new interactive tool will help you consistently track important Parkinson's symptoms and allow you to identify any changes in symptoms to make your visits with your healthcare professionals focused and productive.

APDA is so proud to invest in patient services and education and to have been a funding partner in most of the major Parkinson's disease scientific breakthroughs that are improving the quality of life today. To do all of this, we rely on the support of the entire Parkinson's community. If you are interested in supporting us or want to learn more about how you can get involved, please visit our website at apdaparkinson.org

Our thanks again to our speakers and our sponsors, Acorda and Lundbeck, and to all of you for joining us today. We all agree that being informed about your disease and treatment options is the best way to empower yourselves and take control of your care. Have a wonderful day.