



Speech Therapy and Parkinson's: The Victory Summit Boise Event Session

Recorded on November 14, 2020

Davis Phinney Foundation

Melani Dizon (Director of Education and Research, Davis Phinney Foundation):

Cynthia Fox is the CEO and co-founder of LSVT Global, Inc., which I'm sure many of you have already heard about. Maybe you've taken classes with them. And she was instrumental in the translation of treatment principles from LSVT LOUD to LSVT BIG. She serves as faculty for LSVT LOUD and LSVT BIG training and certification courses. She's an expert on rehabilitation and neuroplasticity and the role of exercise and the improvement of function, consequent to neural injury and disease. Thank you so much for being here today with us, Cynthia.

Cynthia Fox (Ph.D, CCS-SLP)

Thank you for having me. I went ahead and pop my slides up there. Can you see them okay?

Melani Dizon:

Yeah, I can see them. It's all good. You're good to go.

Cynthia Fox:

All right. Thank you. So welcome everybody. And first of all, I'd like to thank the Davis Phinney Foundation for inviting me to join what is so far been such a wonderful conference, and it's great to be here. A little about me—I started work in Parkinson's disease in 1994. It's where I began my career, and it's been 25 years of working and growing and learning. And I can say it's been so exciting to see how, while we still don't have a cure—and of course that's what we want—but how much has improved for people living with Parkinson's disease. And organizations like the Davis Phinney Foundation are one of the backbones of helping people live well with Parkinson's disease during the time they have it.

So now we're going to take a switch and talk a little bit about speech swallowing and communication. So I'm going to highlight some of the motor and non-motor impacts that Parkinson's can have on speech swallowing and cognitive aspects of communication—define the role of the speech, language pathologists, talk about behavioral treatments and strategies. I want to touch on a few device-based aides, some community activities, and of course, the action steps for you. Lots to cover.

You have a handout, again, similar to the previous presentations, that you can download. And I also included a handout that has some tips about having Parkinson's and communicating wearing masks. And certainly that was how we kicked off today talking about the importance of that, but it can make communication a bit more challenging.

Speaker 1 (02:23):

Davis Phinney Foundation

357 S McCaslin Blvd, Ste 105
1-866-358-0285 | contact@dpf.org

Louisville, CO 80027

So let's talk about the prevalence of these challenges. We know that over 89% of people with Parkinson's will have changes in their speech and voice, and these can occur very early. Up to 80% of people will have swallowing changes. And as the disease progresses, it can become even more predominant. And 20 to 43% of people have some degree of cognitive changes. These may be mild, but they can actually occur upon diagnosis. And the prevalence rate for Parkinson's dementia ranges from 28 to 41%. So the point here is these are common things that happen as part of Parkinson's disease, but the good news is there're things we can do about it.

And asking the question, “Well, does it matter if my speech changes or my swallowing changes?” And absolutely it does. Even people who are clinically asymptomatic for speech deficits actually report some feelings of embarrassment or social stigma and social isolation due to speech concerns. People with Parkinson's disease may have decreased joy from eating and drinking. This is so important, as it's part of our socialization or our fabric, to have meals with family, and that piece of it.

And of course it can also have negative impacts on nutrition and the risk of getting an infection or pneumonia due to aspiration. So these are serious problems and we need to address them to help improve quality of life for people with Parkinson's.

Now, what are some motor basis? Well, there's a loss of motor energy and movements are under-scaled. We heard about this from both Hannah and Amanda, how it can affect the body, but it can also affect a speech mechanism. You may not take in as big of a breath. Your vocal folds may not close all the way. You may not open your mouth as wide.

And what can come out is soft speech. Mono-loudness—there's not a lot of pitch inflection. Sometimes the voice quality can be hoarse or harsh or breathy. And in precise articulation, these challenges can also have an impact on swallowing.

Just a few examples: again, the vocal folds may not close all the way, putting you at risk for food or liquid getting into the lungs. It may be more difficult to keep food or liquid in your mouth. And some reduced coordination of the swallowing process. Those are motor contributions, but it's so important to recognize that speech and swallowing are more than a motor disorder. And there are sensory processing deficits that also contribute to speech and swallowing challenges.

So reduced awareness of the speech deficit is very common, and we hear all the time from the person with Parkinson's. “I think my speech is fine. My spouse needs a hearing aid.” And that's part of the sensory problem—that your speech may sound the same to you as it always has, but to others it's gotten more difficult to hear. So if you're not aware, oftentimes you don't correct. And the speech deficit can continue, similarly with swallowing, that oftentimes you may not be aware.

And when we make improvements, it often feels too much. So there's a common phrase—for

example, with speech, when we get somebody louder, they say, "I can't talk like this. I feel like I'm shouting."

In terms of changes in higher cognitive function—Amanda discussed some of these as well—
sSlower thinking may result in slower response time to questions. So sometimes people with Parkinson's rightfully so get frustrated when people don't wait for them to respond, talk over them or talk for them.

In terms of language, we know that sometimes it's harder to come up with the word that you're thinking of. It may be more difficult to shift communication topics. And so when we put all that together, kind of the slower processing, maybe increased levels of distractability—it can lead to loss of train of thought, making longer conversations more difficult and frustrating, both for the person with Parkinson's and the communication partner.

And we also know, and I think Connie and Davis mentioned this in the beginning, cognitive challenges can get worse. The more fatigue a person feels, more tired or OFF medication times.

Similarly, there can be subtle changes in feeding and swallowing. Lack of attention to meal or food selection can prolong mealtime. Certainly there's challenges with the process of eating that can occur. And again, I go back to that social interaction. How much of our joy in life, of mealtime, comes from communicating in that time with loved ones. So quality of life can be affected as well as nutrition.

So when we put this all together, it's not simple. You know this because you live with it. Parkinson's disease is complex. So we have motor challenges. We have sensory challenge, we may have cognitive challenges. And what I haven't mentioned yet—there can be emotional changes, things like apathy, anxiety, or depression that may make taking that first step to improvement just a little bit more challenging.

Unfortunately, classic medical treatments alone will not sufficiently improve swallowing, communication, and speech in people with Parkinson's. Both from a neural pharmacological perspective, there's no evidence of systematic improvement and dysarthria yet—that's another word for the speech disorder—and in terms of neurosurgical interventions, not only may it not improve speech, but we actually know for some individuals, it may exacerbate a speech problem or create a speech problem that was not there prior to surgery.

So the picture was not really very rosy when I began my work many years ago. In fact, in 1987, there were no effective speech treatments for people with Parkinson's. In fact, voice treatment for disorders that are degenerative was actually considered controversial because there was no expectation for recovery of function or that any improvements secondary to our intervention would be maintained. Until recently, behavioral treatments for Parkinson's resulted in minimal and short-

term goals. Well, the good news is that's not the case today. And so let's talk about what we can do and how we can make a positive difference in speech in swallowing and communication for people with Parkinson's disease.

So as a speech language pathologist, our role is to assess and treat these types of disorders. And we have very Parkinson's-specific approaches. So it's not taking our general knowledge and applying it to Parkinson's. But through research over the past 30 years, we have very specific approaches that can be tailored to people with Parkinson disease.

We want to start typically with that assessment. So some type of voice and speech evaluation. We also do swallowing evaluations and treatment. We can evaluate and treat cognitive linguistic strategies. And again, we implement evidence-based practice. This is not just for later-stage Parkinson's disease. We have a role in early Parkinson's disease as well, because we know some of these changes in speech swallowing and cognition can occur early. We say it's never too early, but it's also never too late. We can intervene at any time to help improve these challenges.

I know many of you are voracious researchers. You like to know what the evidence is. You like to study. And if you are, I just alerted you that our national organization, the American Speech Language Hearing Association has this resource, these evidence maps. These are available to the public and the website is on the slide here. And you can go to the evidence maps, select your filters. And what I've selected here is "Parkinson disease." And it will tell you sort of in a summary format, what is the evidence for speech treatments, language, cognition, swallowing, so that you can be a knowledgeable consumer if that is something you like to explore.

I can tell you based upon the evidence that exists, LSVT LOUD is considered the gold standard behavioral speech treatment. Mostly because it's been around the longest, but also because of the depth of research; we've had three randomized controlled trials, also numerous studies trying to understand why treatment works, so hopefully we can help it make work better. And so we study things like improvements in facial expression, changes in what the listener hears, changes in respiratory support, even changes in brain functioning.

So in this lower right-hand corner, you can see somebody who is in our research laboratory hooked up to lots of transducers that we use to collect data. That is not what you need to do for speech therapy. It is much less invasive than that, but this was certainly what we did as part of our research.

The goal of any speech treatment, however, is really to help you not only improve communication, but through that process, regain some self-efficacy that you now have control again, over communication. And so if we look on the left-hand side here, this is often the scenario before treatment. A person with Parkinson disease has a softer voice that leads to less success and confidence with communication, which may in turn lead to withdraw. And so the person starts to

communicate less and less. With therapy, our goal is really to, for example, train improved loudness through salient intense exercise so that you now have success with communication. There's less withdraw, and you become a more competent communicator and in stay engaged and participating in life activities and communication.

So elements of successful speech treatments and things to consider: most successful treatments have had this focus on voice or vocal loudness. They need to be sufficiently intensive. They need to have sufficient repetitions of exercises. They need to develop in complexity over time and include sensory retraining. And I think you've heard these sort of principles of plasticity from multiple presentations here today. And it's because they are that important.

All right. So let's now take a little break from the slides here and let's practice some of these exercises. So what I am going to do is demonstrate a few of them. The first one is just a nice big arc. So we're going to take a deep breath and do a nice—and hold that. We'll go about 10 seconds. So on the count of three, I want you with me to do that. Nice, big breath. So here we go. Three, two, one.

Excellent. For some of you, that may have been easy. Some of you may have felt that that was a little bit of work. And it should be—that's what will help you get a stronger voice. Let's do it again. Same thing, nice long arc. And the count of three, three, two, one.

Excellent. My voice may have cut out. Part of that is Zoom. It it likes to auto-correct things. If you have your water with you, which you should, go ahead and take a drink. Hydration is good for everything. It's good for your health. It's good for your voice. It's good for just keeping you generally energized. So we promote lots of good water drinking, as we heard in the beginning.

Okay. The next exercise now is saying, “ah,” and going high. So we're going to go ahead. And we'll hold that for five seconds. So on the count of three, three, two, one,

Very nice. Let's do it again. The same thing, three, two, one.

Perfect. These exercises, highs and lows, can help with intonation. So if your voice has gotten a little flat, this will help give some of that character and that expression back to it. So what goes up must come down. So now we'll do the exercise.

When you're ready. Three, two, one. Okay.

Perfect. And again, same thing, three, two, one.

Excellent. Now obviously “ahs” are not speech, but what those type of exercises do is kind of rescale your amplitude, rescale your effort, that we then want to train into speaking tasks. So let's

try that. Now. I'm going to say a phrase. I want you to say it after me with that same loudness that you had when you did that nice exercise. So let's start with "good morning." "I love you." "What's for dinner?" Keep it nice and loud. "Where are my glasses?"

Okay. When you got a little bit louder, it might feel kind of funny to you. And if it does, it feels a little too loud, it takes time, it takes repetition. It takes practice to make that really feel like a part of your daily communication, as well as a part of the process is the sensory retraining and helping you recognize that maybe what feels and sounds too loud to you, others perceive as within normal limits.

Okay. So I hope you enjoyed that practice. Let me see if I can get back to my slides effectively here and share my screen again. I believe it's up there. If Mel, please let me know if you're not seeing it. Thank you. Thank you.

Okay. Let's talk a little bit about swallowing treatments now. What the first step really is to request a swallowing evaluation if you or your loved one may have noticed some changes. This can include things like visualization of the swallow. Sometimes it's done through a modified barium swallow study or a fiber-optic endoscopic evaluation. This allows the speech therapist to really understand exactly where in the process of feeding, chewing, swallowing the challenges are happening.

Then they can make recommendations that are very tailored to you. These might include things like exercises to strengthen your swallow exercises, to improve coordination exercises, to improve breathing, and a more efficient cough. And actually there's some very nice research data on Expiratory Muscle Strength Training. That's what the E M S T stands for.

And again, if we get into trouble with food or liquid perhaps going where it shouldn't be, our best defense mechanism is a gone a very strong cough to get that out. Sometimes they may teach you compensatory techniques like a chin tuck when you swallow and sometimes modifications to your diet may be another potential.

Another important piece of swallowing is good oral hygiene. Everything that goes wrong with stiffness, tremor, hypokinesia can make keeping our mouths clean more difficult. The challenge with not having good oral hygiene is that if food or liquid then gets into the lung, it can contain bacteria. And it's actually the bacteria that puts us at risk for things like aspiration pneumonia. So having that good oral hygiene, working with your occupational therapist, perhaps if you're having some specific challenges with that is so very important as well.

And then these are just some general tips tips to take away that you can implement immediately. Limit the distractions. Chew thoroughly. Don't take another bite of food before making sure you swallow your first bite. Swallowing twice. Sometimes what we call "swallow harder" than you think

you need to. So a really effortful swallow can be helpful. And again, staying well hydrated is another really important key for, for general.

What about changes in cognition? Again, these start with an assessment, and really a person-centered assessment for treatment planning. So working with somebody can help identify where in particular some of the cognitive challenges are happening. Sometimes we may interview the family. We may do an evaluation of your environment. This can be done by the speech therapist, sometimes in collaboration with the occupational therapist as well, to determine best locations for things like feeding, eating, and communication. And then you may be prescribed direct cognitive rehabilitation. This can include compensatory strategies, exercises to stimulate attention, memory processing, and some computer-based cognitive training.

Some general tips. Sometimes, at times, we may need to do more intensive treatment or increased dosage to make improvements. Oftentimes we may engage family and caregivers to help with carry-over of treatment strategies, reducing again, distractibility and background noise for the patient. This is for both the person with Parkinson's and the person he or she is communicating with. Allow time for delayed auditory processing; count to five, count to 10 before you ask another question or try to speak for somebody. Define the topic of discussion, maybe ask yes/no clarifying questions to kind of help figure out exactly what you want to be understood.

Simple general tips that are good for all of us, with or without Parkinson disease. But certainly if there's some early cognitive concerns—exercise, and I think we can all wrap our brain around exercise is good for pretty much everything. Socialize, stay active. I know it's hard right now during COVID, but I know every Parkinson's organization is offering so many opportunities such as this to get online, to get engaged and communicate. Work your brain. Engage. If you're stuck at home, find some nice cognitive activities to do go or other things online that keep your brain engaged.

Learn coping strategies with speech and occupational therapists. Nutrition can also affect cognition; eating well, eating a Mediterranean diet. And again, take time, give yourself a break, take time, perhaps planning tasks when you're feeling more at your best versus when you're more fatigued.

A few device-based aides that are out there can also be used. Sometimes people use, in addition to speech therapy, a personal amplification. This is a portable microphone speaker that can further amplify speech, especially in situations where there may be increased background noise. The LSVT companion is an at-home LSVT LOUD training software system that can be used.

Speech Easy is a device that goes in the ear, not unlike a hearing aid. And it can be used for individuals who have what we call hyper-fluent speech. This might be stuttering-like behavior, or sometimes when you start to speak, this gets very fast and very difficult to understand. So a speech therapist can work with you, and it alters your auditory feedback, which sometimes breaks that loop of getting stuck and can help improve speech intelligibility.

The Speech Vibe is a device to increase loudness. So again, it's an ear device, and when you start talking, it puts noise in your ear. So it uses a reflex that we all have, that if we're in noise, we tend to talk louder.

And then other augmentative devices can exist. I have a picture here on this slide, actually just a simple picture board that you can use to point to things that you want to communicate. This can be used in times, perhaps if you get stuck in OFF times that everything becomes very difficult, it might be a way that you can express what you need. I think another consideration for this is if you have to go into the hospital, you may want to put together—this goes back to preparedness—put together your picture board so that if you're having difficulty communicating with with staff, you can be able to point to things that are important to you.

Community-based activities, and I've highlighted singing here because I think it's the most common and a recent paper summarized about 26 publications describing singing in people with Parkinson's disease. And I think the summary is, it doesn't replace speech therapy, so it may not improve speaking communication, but it can absolutely be complementary. And more than that, we know there are great benefits, social and therapeutic benefits, of music and singing and coming together with each other. There are lots of singing groups out there. I put one example, Tremble Clefs, on the slide. I believe there's a sing loud group with the American Parkinson Disease Association. And many of these are being done virtually right now. So we don't have to give up on that just because COVID perhaps has us at home.

So your action steps then are, first of all, recognize speech and swallowing may be changing. And you may not be noticing that. That means you may have to rely on those others around you. If people are asking you to repeat, while they may be have changes in their hearing, likely your voice is getting soft.

So we say, don't wait to act, find a speech-language pathology professional who can partner with you. There's lots of us out there; we're eager to help. ASHA, again, is our our national association. They have a “locate a clinician” on their website. I know the Parkinson's.org has an expert care team. LSVT Global has a certified clinician database. Locate an individual, develop a bond, because you can have treatment strategies across your lifetime of living with Parkinson's learn more. Every Parkinson's organization, including the Davis Phinney Foundation, has lots of free resources out there on speech, swallowing, and cognition.

Engage in intensive treatment. Keep practicing when it's over. If you don't use it, you lose it. You have important things to say. People want to hear you. They want to stay engaged with you. And so give yourself that gift of improving speech, swallowing, and communication.

As I mentioned, there are some device-based aides. If you need them, use them. You may not need them all the time, but they are there and can help. And get engaged in those community-

based activities that you enjoy. And I think this has been a theme as well, with exercise, with occupation. Find things that are meaningful and interesting to you. It might be singing. It might be volunteering, work at your exercise classes, book clubs that could be in-person or virtual, or simply reaching out and talking with your family and friends. One of the things I always like to say as well as just do it—motivation typically comes after you start a new behavior, not before. And so if you're not feeling particular motivated—and we know that can be a challenge—just do it. And I promise that motivation will kick in very quickly.

In conclusion, I just always like to end with this quote from Daniel Webster, very wise words. “If my possessions were taken from me with one exception, I would choose to keep the power of communication, for by it I would soon regain all the rest.” And I can't stress that enough. Your ability to share your thoughts, your feelings with loved ones is so valuable. And it's so exciting because today there is so much we can do to improve communication, improve swallowing, improve cognitive functions related to communication as well. So with that, I will stop. And I thank you very much for your attention.

Want to Watch a Recording of this Victory Summit Event - Boise Session?

[You can access the recording here.](#)

Want More Parkinson's Advice?

Much more can be found in the Every Victory Counts® manual. It's packed with up-to-date information about everything Parkinson's, plus an expanded worksheets and resources section to help you put what you've learned into action.

[Request Your Manual Now](#)

Thank you to our 2020 Peak Partners, **Amneal** and **Kyowa Kirin**, with special support from **Adamas**, for making it possible for us to print, distribute, and ship the Every Victory Counts manual for free.