



**The Victory Summit® Virtual Event:
Our Voices, Our Stories: For People with Parkinson's,
By People with Parkinson's
“Dos and Don'ts of a Doctor's Office Visit”
Davis Phinney Foundation**

Polly Dawkins (Executive Director, Davis Phinney Foundation):

Jackie Hanson:

In the following role play Edie Anderson, Davis Phinney Foundation Ambassador and person with Parkinson's is meeting with her movement disorder specialist, Dr. Haug, and offers an example of what not to do when it's your time to meet with your doctor, whether in person or virtually. As you watch, see if you can list the don'ts of the following example.

Aaron Haug, MD (Movement Disorder Specialist, Blue Sky Neurology):

Oh, hi Edie. How are you today?

Edie Anderson (Ambassador, Davis Phinney Foundation):

Oh, hi, Dr. Haug, I am fine. Thanks.

Aaron Haug:

Good. Good to see you. Is Scott gonna be joining us?

Edie Anderson:

Oh, not today. He's got something else to do and, well, it's kind of my fault. I didn't check his schedule before I made this appointment, so it's just us.

Aaron Haug:

Okay. Well sometimes two sets of eyes and ears are better than one, but one's still better than none. So, we'll make the best of it. So, let's see, looking at my notes here. Do you want, do you have a pen and paper? Are you gonna be taking any notes as we talk?

Edie Anderson:

No, I'll remember what you tell me.

Aaron Haug:

Okay. I'll take notes for both of us. All right. So, looking at what we did last time, you were having that pain and numbness in your arms and hands, and I, we had talked about physical therapy. How did that go?

Edie Anderson:



Well, it helped a little bit.

Aaron Haug:

Okay. Did they have any specific recommendations for you?

Eddie Anderson:

Well, they gave me some exercises, but I kind of lost the sheet they gave me with the instructions, so I never really did them much at home. But what they did recommend that helped more, they told me to sleep on an adjustable bed, 'cause I was using a lot of pillows to kind of prop up my neck and shoulders and they said that might have been causing some of the problem. So that did help.

Aaron Haug:

Okay. Well, I'm glad that helped. Regarding the exercises, I don't wanna suggest anything else until we've seen how those exercises work. So maybe follow up with PT, see if you can get those exercises again and try to be a little more consistent, write down what results you get out of that. And then we can get go from there.

Eddie Anderson:

Yeah, I'll try. I'll try.

Aaron Haug:

Okay. Now what about your tremors... last time we talked about a medication change. How did that work?

Eddie Anderson:

Hmm, I really didn't like it. I didn't like the way the medicine made me feel.

Aaron Haug:

Okay. That's disappointing. I was hoping the new meds would do the trick. Can you tell me what particularly happened with it?

Eddie Anderson:

I don't remember exactly, but it made me feel funny and I think it gave me heartburn or was it stomach cramps? I can't remember.

Aaron Haug:

Okay. I'm sorry to hear that. Was there anything else you wanted to talk about today?

Eddie Anderson:

Not really. I was thinking about something earlier, but I forgot what it was. So, I guess we're, I guess that's all.

Aaron Haug:

Okay, well I'll send a refill of your prescriptions to the pharmacy, and we'll set up a follow up for a few months.

Eddie Anderson:

Okay. Well thank you.

Aaron Haug:

You're welcome. Good to see you.

Eddie Anderson:

Bye.

Jackie Hanson:

So, what were the don'ts that you noticed during this appointment? You may have noticed that number one, Edie did not schedule her appointment to be able to include her care partner or a friend and family member. This may not always be possible, but if another person is able to be present, they provide additional insight and create a more well-rounded picture for your physician. Number two, she did not follow through on the exercises her physical therapist gave her to do. Until she does, Dr. Haug is not comfortable recommending anything else. This means that if the physical therapy exercises don't have an impact on her symptoms, Edie will have to wait another six months to try something new. Number three, Edie did not track her medications or responses to her medications. Because of this, Dr. Haug is again, not comfortable recommending any changes to her current medications because without more detailed information, there are too many variables in risk and or effectiveness. Number four, Edie did not come prepared with her top three topics that she wanted to talk about for the appointment. As you noticed at the end of the appointment, while she had been thinking about something she wanted to bring up earlier that day, in the moment, she couldn't recall what it was. Now, let's rewind this scene and see how the appointment goes differently.

Eddie Anderson:

So, I filled out this worksheet for the symptoms that you know, I have, and it, you rate the symptoms from one to five and I've got three that I think are in the five category, and those are the things I need to talk to the doctor about. So, here's your copy. Do you think that's right? What do you think?

Scott Anderson:

Yeah, definitely speech and yeah, absolutely. All three of 'em.

Eddie Anderson:

Okay. All right. Well, we're all set for the doctor then.

Scott Anderson:



Alright, let's go.

Aaron Haug:
Hello hello. Hi Edie. Hi Scott.

Eddie Anderson:
Hi, Dr. Haug, how are you?

Scott Anderson:
Good to see you.

Aaron Haug:
I'm doing well. Yeah. Nice to see you guys again. How are you today?

Eddie Anderson:
Good, Good. Nice to be here.

Aaron Haug:
Good. Good. Well, thank you for bringing in the checklist of symptoms. I was just looking at that and looking at the last note that I had from our last visit. And one of the things we had talked about that's on your list of concerns again for today is the pain and numbness in your arms and hands. And we had talked about physical therapy last time. How did that go?

Eddie Anderson:
Well it really helped a lot. Don't you think?

Scott Anderson:
Yeah, definitely. Definitely.

Eddie Anderson:
They made some good suggestions. I had been sleeping on a lot of pillows, which kind of made my neck and shoulders kind of crunch up. And so, they said if I could use an adjustable bed, which I happen to have, so that's made it better. And the numbness is a lot better than it was, and also the exercises we did were good. As a matter of fact, I have a video of those exercises. You wanna see it?

Jackie Hanson:
Dr. Haug takes a look at the video Edie has brought in and is able to see exactly what movements she's been doing at home, as well as how she's been doing them.

Aaron Haug:

Okay. Well, that's great. I'm pleased to hear that the PT has been feeling helpful and seeing the video, I think you're doing a good set of exercises that'll be helpful with those issues. And now you can keep working with PT on some of the other trouble spots that you've been dealing with. Now, what about the tremor? Last time we talked about a medication change. How's that going?

Eddie Anderson:

I think it's been helpful as far as controlling the tremor more, but it doesn't seem to agree with me very well. I've got some pretty troubling side effects from it.

Jackie Hanson:

At this point, Eddie pulls out her symptom and medication tracker, where she has been keeping a detailed record of how she's felt and when she's felt it in relation to her medication timing and shows it to Dr. Haug.

Aaron Haug:

Okay, well, that's helpful for me to know what the cause and effect is there. So, I think that that is probably related to the medication and we'll try a different change today.

Eddie Anderson:

Okay.

Aaron Haug:

What else, any other questions or concerns while we're together today?

Eddie Anderson:

Well, this one's hard to talk about and it's kind of embarrassing, but it's the whole constipation thing. I'm really having a hard time with that. And it doesn't seem, I mean, I take a laxative but I don't think it's working right.

Aaron Haug:

Okay. Well, I know this isn't easy to talk about, but thank you for bringing it up. This is a super common thing, and there's a lot of options that we can use to address it. So, let's talk more about some of those

Eddie Anderson:

I go from one extreme to the other, and I need to kind of figure out the middle road here. Do you have any suggestions?

Aaron Haug:

Okay. Well, I think that this is a common thing where it kind of swings back and forth. So, since you've been keeping track of your symptoms, it seems like you've kind of gone several days

with constipation then it swings to diarrhea. So, I think that if we're able to get you on maybe a consistent regimen, maybe a little bit of a laxative every day, that that may really help

Eddie Anderson:

I'll try it. I mean, I really, I need to do something for it.

Aaron Haug:

Okay. Well, in addition to all those things, I also wanna ask Scott, is there anything else that you'd like to add that we haven't touched on yet?

Scott Anderson:

Well, the only thing I can think of there's been a little bit of forgetfulness that I've noticed over the last month or two, not about anything big, but maybe small appointments that we've made that I've mentioned to her that we were, I thought we were both aware of and she doesn't seem to remember that we were gonna go to the beach at a certain time or go to a certain place at a certain time. And I think part of that is maybe I'm not paying attention to the fact she's already preoccupied. And as we all know, it's very difficult with Parkinson's to do more than one thing at a time. So that could be part of the problem, but I did notice that.

Aaron Haug:

Well, I think that's a good point. Eddie, is that something that you've noticed?

Eddie Anderson:

Well, we talked about it a little bit before we came here today, so I knew he was gonna bring that up and I don't feel like, I mean, I don't realize that I forget some things, but obviously I do, but I think he's right. You know, I can't concentrate or focus on more than one thing at a time. So, if he tries to, you know, tell me to do something or we make an arrangement and I'm somewhere over here, then it's gonna get lost. So, I think that's something we need to work on.

Scott Anderson:

Yeah. If I get the hand I know I should stop, sometimes I get the hand.

Aaron Haug:

Well, I think that's a good way of providing that feedback. I can just validate what you're saying here, which is that multitasking is one of the more challenging things. So sometimes the adaptation of simplify and adapt and avoid multitasking is a good strategy.

Eddie Anderson:

So, you can help.

Scott Anderson:

Yes, I can.

Jackie Hanson:

So, what were the dos that you noticed in this appointment that may have been missing from the first example? You may have noticed that number one, Edie did schedule her appointment to be able to include her care partner Scott. Because of this, Scott was able to provide additional information to Dr. Haug to be able to create a more well-rounded picture of Edie's overall wellbeing. Number two, Edie did follow through on the exercises her physical therapist gave her and had a recorded video of the movements. The video not only helped Edie to remember what she was supposed to do, but it also better informs Dr. Haug to be able to suggest additional treatment. As you noticed, because Edie followed through on her exercises and tracked her improvements, Dr. Haug feels comfortable advising her to now spend her limited time with her physical therapist, working on other trouble areas while continuing the exercises she's currently doing.

Number three, Edie did track her medications and responses to her new medications. Because Dr. Haug has this detailed information, he now feels comfortable suggesting a new medication to try. Number four, Edie did bring up a topic that was important to her, even though it was embarrassing. By doing this, not only did she get a treatment plan from Dr. Haug that will hopefully improve these symptoms, but Dr. Haug also validated that this is a common symptom and she should not feel embarrassed.

Number five, Edie did come prepared with her top three topics that she wanted to talk about during the appointment. Because of this, she was able to have Dr. Haug address all of her top concerns. Additionally, you may have noticed that Edie discussed these topic areas with Scott before the appointment. This again, allows Scott to contribute something that perhaps Edie herself has not noticed. And by having this conversation beforehand, Edie is not caught off guard when Scott brings up her memory difficulties in the appointment. This is a lot of information to remember it once. So, in addition to creating this scene for you today, we sat down with Dr. Haug, Edie, and Scott, and asked them that if you were to walk away with just a few things to remember from today's session to help you have better appointments, what would they be?

Aaron Haug:

Well, I think that we kind of captured them pretty well here. I think the big first point is if you are not thinking about what you're gonna say in the doctor's visit, until the doctor walks into the room, you're gonna lose a lot of potential useful interaction that could happen there. On the flip side is, I occasionally will have patients who come in with 20 different symptoms tracked over the last 90 days. And it's almost too much data. And so, I think coming into the appointment with two or three things in mind that you either wanna make sure the doc knows, or that you might be interested in a medication adjustment for and setting the table early with those, with that part of the agenda I think makes it go better for everyone involved.



Eddie Anderson:

I think being prepared for the visit is extremely important because it makes a very efficient use of time, both yours and the doctor, because the doctor's busy and if you're not prepared and you're just wasting his time, then he's not gonna stay in the room with you very long. So, it's important to come prepared. Also, ask questions. People often say to me, my doctor never tells me anything. And my, and I say, well, did you ask him anything? So, you need to let the doctor know you have questions in order to get the information you want. And lastly, I think it's important to go with a positive attitude and to be prepared to be compliant with whatever the doctor recommends in the way of trying new medications or doing exercise or doing whatever he recommends to make things better. So those would be my top three. You got more to say?

Scott Anderson:

Well, I have two, the one is of course being present at all of our neurology appointments. The only time we haven't done that is during COVID when I couldn't. And the reason for that is, one of the important reasons is to get to know the doctor myself, it's all well and good that she knows him, but I also wanna understand how the doctor operates and what kind of a person he is, because then I can, I can kind of anticipate things that I might have to bring up that maybe he's not paying attention to, but secondly, to look at Eddie's notes, she hands me the notes before we go to the meetings, and then I can start thinking about the things that I need to chime in with when the doctor finally gets to asking me that question.

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