



Parkinson's Care Partner Training

Session 3: Parkinson's Medications, Complications, and Advanced Symptoms

Davis Phinney Foundation

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

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

Thank you for being here. I am Polly Dawkins from the Davis Phinney Foundation, and today is the third session of our Care Partner training program. And today, we'll be focusing on Parkinson's medications, complications, and advanced symptoms of Parkinson's. And we are so lucky to welcome Serena Hess. Welcome, Serena.

Serena Hess, MA, MSN, RN:

Morning. Thank you for having me.

Polly Dawkins:

Good morning. So, we have one hour together today, a really quick session, and Serena has so much experience from working in our community. So, first, hello again, Serena, and

Serena Hess:

Oh,

Polly Dawkins:

Let's, let's get straight into it. Tell us, you know, tell us who you are and your background.

Serena Hess:

Sure, no problem. So, I am a nurse, and I previously worked at the Rush Movement Disorders department with Dr. Jorie Fleischer. And I was fortunate enough to work under her, with a grant where, we had this amazing program where we were able to go visit people with advanced Parkinson's in their homes for four times a year. So, every three months, I would visit with the patient and their caregiver. And we also would have a licensed social worker with us too. And each visit, we did a safety check, a medication reconciliation, vital signs, you know, the UPDRS simulation discussion. We would do a mental health check-in for any resources that were needed for the patient and the caregiver. And then, we would move on to a telehealth visit with our movement disorder specialist, aided by myself. So, we really found that it was an amazing program, not only for the patients, but also for their caregivers, who oftentimes just



felt like they were very isolated and didn't have the resources maybe that they needed. So, I was very happy to help connect them with those resources and just give them some extra support.

Polly Dawkins:

So, in the scope of the time that you were doing those visits, how many visits would you say that you did?

Serena Hess:

So, let's see. Let me do some quick math here.

Polly Dawkins:

It's approximately.

Serena Hess:

Ten or I'd, 300. 300 visits. Yeah, 300 visits. 300

Polly Dawkins:

Visits, yeah.

Serena Hess:

So, you have

Polly Dawkins:

Seen a lot.

Serena Hess:

I have. And it was interesting. We started these visits pre-pandemic and then continued them throughout the pandemic. So, then that became an even more necessary, I think, event for people to visit with us. That was usually their last visit, the fourth one that happened all via telehealth because of the pandemic. But the beauty of it is that at that time, we taught them how to use telehealth, so you know, it was a really helpful situation.

Polly Dawkins:

Yeah, absolutely.



Serena Hess:

Yeah.

Polly Dawkins:

Is your background as a nurse is really focused on geriatrics, or was it focused on geriatrics before the additional training that you're doing now?

Serena Hess:

Yes, it was. And now I am currently in school and will be shortly graduating with a psychiatric nurse practitioner a certification. So, I'm really looking forward to going into that. And my experiences with these wonderful Parkinson's patients and their caregivers are very near and dear to me, and I will continue to think about that when I become a prescriber. So.

Polly Dawkins:

Wonderful. Well, we should all be so lucky to have somebody with your expertise on our team, and that's why Oh, that's why we'd love to share some of what you've learned over the Sure.

Polly Dawkins:

Three hundred visits and more in your career. So, today, we're going to be talking about Parkinson's medications, complications, and advanced symptoms. But it's important to know for those care partners in the audience that we can't answer questions about your specific situation and your own medication or your person's medication regimen. So, we'll be talking about them broadly. If you have really specific questions about your own or your family's medical medications, we recommend that you take that back to your movement disorder neurologist and your general practitioner. Is that, is that fair to say?

Serena Hess:

Yes, I think that is very fair to say Great.

Polly Dawkins:

Great.

Serena Hess:

Yes, because everyone's, you know, practitioner and movement disorder specialist do things a little bit differently. So, I think we can talk about overreaching type goals and thoughts that I've seen that are, you know, applicable throughout the community. So, super, super. Yeah.



Polly Dawkins:

So, if, as you reflect back to all of those home visits you did, what would you say are some surprising things that you wouldn't have known if you hadn't gone into people's homes? Things that stand out as, as things that were challenging for care partners and to manage or,

Serena Hess:

You know there, I think there's so much for a caregiver to manage.

Serena Hess:

You know a lot of, one of, I'm going to talk about some of the common themes. One of them, the big one, was the isolation of the caregiver. The sense of loss of the life that they thought they were going to have with their partner, and now they've become a caregiver. Also, just like the act of finding someone to stay home with their loved one with Parkinson's, just so they can go grocery shopping or get their hair done, or maybe go to a Pilates class, and now all of a sudden, you know, they're handling the house budget on their own, they're handling the house repairs on their own. And then the big one is, you know, the caregiver's own health issues, right? That is sometimes being ignored or not addressed, because by the end of the day, they're so tired, they don't have time to deal with the surgeries that they were supposed to have as they're aging or the back issues they're now having, or, you know, all of, or their own mental health, which when you are in that isolation can get to be pretty high.

Serena Hess:

So those were some definite themes that I kept seeing over and over again, and we were really, you know, hoping to help those wonderful caregivers through that year to help address some of these needs. Yeah.

Polly Dawkins:

Were there strategies that you all came up with or that care partners taught you about how to manage some of those?

Serena Hess:

You know, yeah, I think in general, as a society, you have to ask for help, and it's very hard to ask for help sometimes. Right? Whether it's asking for help from your own children, asking for help from your friends, asking for help from your community of, you know, a church or whatever. And I think once you can get over that first step of, okay, I need to ask for help; then I think you realize you are part of a bigger community and that there are people there to help you and that you're not saying, I can't do this anymore. You're just saying, I can't do this by



myself anymore, and so, yeah, I think asking for help, it seems like such a simple thing, but it's a really big thing. So, I think being able to ask for help, number one, is a huge item.

Polly Dawkins:

Did you see or have ideas of how people learn to ask for help? Or did you see ways that they, that our care partners, were able to say, oh, maybe this baby step I can ask for this?

Serena Hess:

Yeah. You know, they would say things like, oh, well, my best friend said that she would come over and bring me dinner. Still, I didn't want to bother her. And, you know, just saying, if people are offering, it's okay to say yes and also telling some of the care partners that, you know, people really want to help you, and they don't know, they feel bad, and they don't know what else to do. So, if they're offering to bring you a meal, it's actually helping them because then they feel like they're helping you. Right? Or if they offer to come and sit with your husband for an hour so he doesn't fall down, and you know, they'll play cards with your husband, so you can go to the gym or go to the grocery store, then say yes, and be graceful about it, and then they actually feel good that they're helping you, too. So, it's, you know, a two-way street.

Polly Dawkins:

Yeah. That's great.

Serena Hess:

Yeah.

Polly Dawkins:

So, as we have built this community, and those of you who are watching today and are part of our care partner community, you tell us that you are worried about Parkinson's advancing. Can you talk with us a little bit about some of the symptoms that are generally considered more advanced and advancing and or feel advanced for care partners as they provide care?

Serena Hess:

Yeah, no problem. Yeah. I think, you know, some of the big ones is that, you know, as we all know, you can live with Parkinson's for a very long time. It, you know, things can be very minimal for a while, but then all of a sudden, you might notice that your loved one is having more difficulty walking, or they need an assistive tool, like a walk, you know, like a walker. All of a sudden, they're having a hard time finding the right word or having a difficult time talking. They could have increased tremors and or rigidity, and then all of a sudden, their normal body functions change. You know, all of a sudden, your loved one is getting more UTIs. They used to

not have constipation, and now there's all this constipation. And then the big one is all of a sudden, your loved one is having more falls, and you don't understand why. A lot of times, it's because they're lightheaded, because they went from being hypertensive and being on these hypertension medications. And then somewhere in the Parkinson's, you know, progression, they go from being hypertensive to being hypotensive, which means their blood pressure drops, and they're getting lightheaded and falling. So, that's also a big sign. And then lastly, you know, kind of the onset of depression, it maybe that we didn't see before and or cognitive changes. So, those are, those are some big ones. Yeah.

Polly Dawkins:

Interesting, interesting. So, as you mentioned UTIs, and that phrase may not be, I'm

Serena Hess:

Sorry, urinary tract infections. Yes, yes. Sorry, that was the nurse and me. I apologize.

Polly Dawkins:

No, that's quite all right. I just want to make sure everybody understands. So, that raises a topic about not everything that we're seeing is Parkinson's, but it can affect the - So. tell us a little bit about aging—Parkinson's.

Serena Hess:

Parkinson's. You know, I can tell you, over the 300 visits that I did, we would go to someone's house, and their care partner would say, oh my gosh, you know, all of a sudden, we're having hallucinations, or their falling more. And honestly, if I can, if you all can leave with one thing, always have them get checked for a urinary tract infection. Because of urinary tract infections, and people with Parkinson's, they are not always symptomatic like we are used to throughout our lives. They can have none of the urgency, none of the burning, none of that. But it just comes out with increased Parkinson's symptoms. So, anytime we would go visit someone's house, and those issues would come up before we did any medication change, we would ask them to get, you know, give a urine sample to their PCP or, you know, urgent care or whatever. And I cannot tell you 50% of the time, they had a simple urinary tract infection that can be handled very simply with antibiotics, and then they would go back to their norm. So, yeah, that was a, that was a big one.

Polly Dawkins:

That is what other, what other things would you see that you could attribute it to? Just aging

Serena Hess:

Constipation, I mean, as we all age, our GI tracts, you know, kind of slow down. Our gastrointestinal tracts slow down a little bit. So, but with Parkinson's, everything in the body is kind of slowing down a little bit. What it is, you know, the synapses that are in our body going to our brain, that becomes a little muddled in Parkinson's. So, as the Parkinson's progresses, the constipation can really increase. And everyone thinks, oh, well, you know, everyone's constipated. That's not that big of a deal. Here's something to think about, though. If you're constipated and there's all that stool backed up, your medications are not getting metabolized in your body the way that they should be. So, it's almost like you're getting a half dose of your Parkinson's medication. So, you know, the other thing was, okay, if you don't have a urinary tract infection, are you really constipated? Oh yeah. Well, my loved one hasn't had a bowel movement in six days. Well, how do you think that's affecting how their medication is working in their body? It's affecting them a lot. So, putting them on some sort of constipation, you know, prevention program is really, really important, too. Yeah.

Polly Dawkins:

We spent quite a bit of time earlier this week talking about poop. Yeah. It's with Dr. Fletcher. So, if you missed that session, I would recommend you all go back and listen to that portion. Because it was really, it was really enlightening in some areas. So,

Serena Hess:

Yeah. Let's, the last, I'm sorry. The last one that we have talked about was blood pressure. You know, we go our whole life trying to decrease our blood pressure, right? It's such a problem in the non-Parkinson population that as you get older, my blood pressure's too high, I have to go on an anti-hypertensive medication. But then, there's not a whole lot of people looking at these anti-hypertensives for people in Parkinson's. Sometimes, they might need to be deprescribed, you know? Yeah. We talked about that as So

Polly Dawkins:

That's

Serena Hess:

Another one. Yeah.

Polly Dawkins:

Well, these things are pretty common.

Serena Hess:

Yeah.

Polly Dawkins:

So, let's talk about the role that medications play in our loved ones; their symptoms are more advanced or more troublesome. How do, how do, how do we think about the re medication regime changing, regimen changing as Parkinson's progresses? For

Serena Hess:

Sure. You know, as you know, we've talked about all the things that maybe aren't Parkinson's, but a lot of, you know, but then once we've kind of gotten through those three things, and it ends up, it is just the Parkinson's advancing. The symptoms are becoming more and more common. What you'll see is a difference in whether or not you're on an instant relief carbidopa-levodopa. Or all of a sudden, your movement disorders doc might say, all right, now it's time to have an extended release one, right? To give you more coverage. Or you might all of a sudden have gone from just taking a morning noontime and a, you know, a dinnertime dose to taking a few more doses throughout the day. So, those are things that I saw in those 300 visits. Also, you know, if cognition becomes a little bit of an issue, you might see an addition of a like a donepezil or rivastigmine, which are those acetylcholinesterase inhibitors.

Serena Hess:

And those can kind of help. Sometimes, as Parkinson's progresses, they might start having hallucinations or delusions. So, that's something that you would want to address with your provider. And then also, like I mentioned before, if depression occurs, let's not, let's not ignore that. Because what happens =with depression, that means your person with Parkinson's is not going to want to get up and move. And we all know the more you move, the better it's, right? So, if we have depression, we want to make sure that we're addressing that with a low, you know ss, SSRI, everyone knows those are the Zoloft, the Prozac's, that type of stuff. And see if we can get our person with Parkinson's back to kind of a baseline mood level so they can keep going out and doing things and keep their bodies moving. So

Polly Dawkins:

Did you see as symptoms advancing that agitation was one of those symptoms? For sure.

Serena Hess:

Yeah, for sure. That could happen, too. And again, depending on what your provider thinks, some providers, you know, handle that with a very low dose of an anti-psychotic, and then that can kind of help with some of that agitation, too. Yeah.

Polly Dawkins:

You mentioned a little bit earlier two names of drugs, maybe for cognition.



Serena Hess:

Yeah.

Polly Dawkins:

Again, so we could capture those for the audience. Do

Serena Hess:

You, what do you want me to do?

Polly Dawkins:

Could you say the names again? So, we

Serena Hess:

Dill O N E P E Z I L. And the other one is Rivastigmine. So, those two drugs were used for cognition for Parkinson's patients. And I want to everyone should know it doesn't improve cognition a whole lot of times, but it can kind of keep them where they're at. Yeah. And they're drugs that are a lot of times used in the Parkinson's community with cognition issues and also in the Alzheimer's community.

Polly Dawkins:

Ah, great.

Serena Hess:

Yeah.

Polly Dawkins:

And then you mentioned a couple of antidepressants that often get prescribed with Parkinson's. Would you mind just saying those names again?

Serena Hess:

Z Zoloft, Prozac. Yeah.

Polly Dawkins:

Zoloft and Prozac.



Serena Hess:

Those are.

Polly Dawkins:

Easier names to remember.

Serena Hess:

Yeah,

Polly Dawkins:

Probably. because They've been advertised a lot.

Serena Hess:

They have

Polly Dawkins:

Super, super. And so, we talked about introducing extended-release levodopa and adding more doses.

Serena Hess:

Yeah.

Polly Dawkins:

Throughout the day. Is that the only strategy that you saw being employed along with some of these cognitions and

Serena Hess:

Again, that just depended on what the provider that I was working for saw. Right. And so, you know, it would kind of just come up on a case-by-case basis. But again, what I would say to the caregivers is that see those other things of the, you know, the urinary tract infections, the orthostatic hypotension, you know, depression. If that stuff isn't happening and it really is the true Parkinson's disease progression, then keep a log of the symptoms and say, this is what has happened this past week. These are the medications that we took, like you told us to do. We've ruled out all of these other things. What are our options now? And that's what I would recommend doing.



Polly Dawkins:

That's a great recommendation.

Serena Hess:

Yeah.

Polly Dawkins:

Great homework. And speaking of homework, we asked people on Monday to do a few takeaways to exercise perhaps or do a few other things. So, maybe the homework for Monday could be to start a medication log if you're starting to see some.

Serena Hess:

Changes

Polly Dawkins:

In a person. I

Serena Hess:

I cannot tell you on, and maybe it's because I'm a nurse, right? But one of the biggest things I recognized when I would come into these wonderful people's homes is that what is really helpful as a nurse or as a provider or even as a physical therapist, if you have a list of medications that your loved one is taking, that you can keep on your computer, that you can edit and then you can just show that to anyone who comes to your house or bring it to any provider that you go to. It is super helpful for us. Super helpful. And then I would come, and I would literally take their huge box of medications and look at the list and compare the two. And that is huge because I would find it unfortunate; I mean, it gets confusing. There's a lot of people taking a lot of medications. You know, the extended-release versus the instant release. And unfortunately, a lot of times, people were taking the medications incorrectly. And so just simply figuring that out and having the caregivers and the patients take their medications as they're prescribed is huge. Yeah.

Polly Dawkins:

Yeah. Then, having watched, you know, my parents try to manage their medications. Yeah. I see. The number of medications, the sort of cognitive load that it takes for a care--

Serena Hess:



To put together-

Polly Dawkins:

His or her own medications, much less somebody else's. Tell us, what did you see, like best case scenario, how did people manage that? And then, what were some worst-case scenarios that you saw? Yeah.

Serena Hess:

You know, the best-case scenario is that the persons with Parkinson's and their caregiver would do this together, right? So, there was some ownership from the persons with Parkinson's. Because if there is that ownership, then they're more likely to take the medications. Alright. Hmm. And so, what would happen is they would have that nice list. Sometimes, it was laminated, which was great, and Sunday would be the day when they would wake up, and they would have their big pill. You know, sorters, I would highly recommend if you don't have one of those, get one and get a seven-day-a-week one with at least four spots in each day. So, like an am a noon, a dinnertime, and a nighttime one. At least four spots. And then Sunday would be, let's drink our coffee and sort the medications. You know. And that was very helpful when it was done together because then, you know, there was a little bit more ownership. Another thing that's helpful is some of those medication tools that they have actually have alarms on them, too. Oh, sure. So, sure. Yeah. So, that's really helpful as well.

Polly Dawkins:

Yeah. That reminds me, we have medication logs at the Davis Finney Foundation. Mel has just put up a link if you want to download those logs in the audience.

Serena Hess:

Wonderful. Yeah.

Polly Dawkins:

But it also reminds me of something that we adult children can do to help our parents. Yeah. If you, if you have adult children or friends who are saying, how can I help coming over on a Sunday and sitting with a person with Parkinson's and doing both meds and doing your you care partner meds and doing per, with the person with Parkinson's, their meds, that's an easy task to give away. It's

Serena Hess:

Suppose you can let it be a huge help. Yeah. I remember we had one family, and their next-door neighbor was a pharmacist. And the pharmacist said, okay, this is how I'm going to help you. I'm



going to pick up your meds every week for you, and then I'm going to come over on Sunday and sort them. And it was literally an hour of that person's time, but that might've been four hours, you know, of the caregiver's time. So, it's a huge help. A huge help. Yeah.

Polly Dawkins:

Yeah. And I also sat and with my mom and her phone, and I programmed in times alarms.

Serena Hess:

Yeah.

Polly Dawkins:

It was helpful for her. And I'm with, when I'm with her, I still see her say, oh, what's that noise? What, oh, my medications.

Serena Hess:

Yeah. So, it might be.

Polly Dawkins:

Something you all, as care partners, might be able to offload to somebody to help, help you figure that out, and do that.

Serena Hess:

Sure. Yeah. It's really easy, and also helps for adult children to do. Right. And it's a nice visit, too. All right. On Sundays, I'm going to come over and visit with your dad and mom, and we're going to walk through the medication. So, it's like a social visit and a, you know, a getting the job done visit, too. Yeah.

Polly Dawkins:

But it's hard to let go. Right. And trust, you have to find somebody you trust to do that.

Serena Hess:

You for sure do, you for sure do. Yeah.

Polly Dawkins:

And be able to let go of that.



Serena Hess:

Yeah.

Polly Dawkins:

Which may not be possible for some, well, some people, it-

Serena Hess:

For sure, it for sure could. But then maybe you have to think about, well, what are some things that I am able to let go of as a caregiver? You know, it might not be this medication piece, it might not be, you know, the cooking piece, but maybe, maybe, if you offer to drive us to our doctor's appointments, great. That's one less thing I need to worry about. So,

Polly Dawkins:

Yeah. Great. Are there any other strategies or things that you can think of that care partners can help with around medication changes or, medication management, or compliance? You've given us some great ideas already.

Serena Hess:

I think that besides that medication list that we were talking about, I think we should go back to the fact about how helpful and important it is to have just a medication log. Right? So, if you are given a new medication or a new dose of Carbidopa levodopa, it just keeps a log, and it can be as simple as the caregiver having a little note on their phone, right? Okay, we started this on this Sunday; this is what happened Monday. This is what happened Tuesday, Wednesday, Thursday, and Friday. Because I tell you what, when your provider checks in with you, they're going to want to know, and the more symptoms or good or bad that you see from that medication change, then that's very helpful for them to determine what their next steps are.

Polly Dawkins:

Yeah.

Serena Hess:

Yeah.

Polly Dawkins:



Thinking back to all of your experiences in homes, tell us a little bit more about, you know, tips that you picked up, things that you would like to share with the community about medications and managing those meds, if you have any others that you want to.

Serena Hess:

Well, I will say this. The one other thing that we didn't talk about is expired medications.

Polly Dawkins:

Oh. So,

Serena Hess:

You know, we talked about the good, the good situations I saw. Then there were also some bad situations that I saw and, you know, people are doing the best that they can, so I understand that. But you know, giving their person with Parkinson's medications that expired two years ago, you know, that's not helpful. And then also the number of times I would walk into a person's house for the first time, and they were taking all of these medications that they never told their providers about the high fall risk medications. like, what

Polly Dawkins:

Are

Serena Hess:

Benadryl? Benadryl is not good. Or the nighttime ones where they can't fall asleep. So, they're like, oh yeah, then on top of all this, I'm taking Unisom at night or Tylenol PM at night. Those are no-nos for people with Parkinson's. Because it can lead to, you know, a lot of fall risk because they're so tired at night.

Serena Hess:

This is up to people's individual providers, but I think everyone knows that benzodiazepines for those older than 65 are risky to begin with. And then when you, like, so the Xanax, right, the Valium, that type of stuff. So, when you add that to someone who's over 65 with Parkinson's, that is a huge, huge fall risk issue, especially in the middle of the night. So, those were some other things that we saw where we gently, you know, recommended to maybe de-prescribe or not be taking the Tylenol PM at night. Because that's just going to lead to falls, yeah.

Polly Dawkins:



So, somebody is asking, are there other medications that you would say we should be on the lookout to avoid? Either for ourselves as care partners or for, in terms of these increased?

Serena Hess:

I think it's a point. Yeah. It's, it's the Benadryl, the nighttime meds that help you sleep, the NyQuil that helps you sleep all. Anything that is sleep-promoting or those high doses of Valium or Xanax, those can really lead to falls. So, just be on the lookout for that. Yeah.

Polly Dawkins:

Great. What were some other things that you saw that you'd say, oh, don't do this at home?

Serena Hess:

Well, you know, it was just simple things. Well, that I thought was simple. So, one of my jobs as the nurse going into their homes is I would do a quick safety, right? A quick safety looks. There, I can't tell you how many times there wasn't enough space for a person with Parkinson's to safely get to the bathroom at night. There would be a throw rug that could just make them trip. It wasn't well-lit enough. You know, so kind of looking around with an open eye of like, oh, you know, what is a safe environment for my loved one to be in? And whether that means having well-lit hallways, keeping a light on at night in the bathroom, you know, if it's time those little rails that you can just stick underneath the bed mattress.

Serena Hess:

Those are huge for Parkinson's patients to use to get in and out of bed easier. Just things like that, just kind of looking around to see if it is this safe or is this not safe? I would sometimes go to someone's house, and I would see like crumbling front steps, you know, just look at that with a fresh eye. And if I thought I was going to fall down those steps, then, you know, someone with a higher fall risk is definitely going to fall down those steps. Hmm. So, just things, you know, simple safety things. Because I mean, we've all been living in our houses for so many years, it's very hard to look at it with a new eye. Right. So, maybe we may be looking at it with a new eye. Yeah.

Polly Dawkins:

And would you recommend that having an occupational therapist come into a home and help do a safety check?

Serena Hess:

Was I going to say that? Yeah. I cannot tell you how much of a partner having an in-home physical therapist, an in-home occupational therapist, and even if needed, an in-home speech



therapist can be your best friend, and they can really help you with that. Physical therapists, actually, there's a billing code for them to do safety checks on people's homes. So, if you know your providers, like, oh, do you want some in-home PT or to? Say yes. And then say, I really need the physical therapist to kind of do a safety check on my house and then be open to what they would recommend. Yeah.

Polly Dawkins:

Great. And do you know how people can activate that? Is it asking their-

Serena Hess:

You ask your provider, and then they can look in and see if there is insurance coverage for in-home therapy. Yeah. And usually there is,

Polly Dawkins:

I know when you and Jorie and the team were going out to people's homes, part of the reason was because they weren't showing up in doctor's offices. Is that, is that correct?

Serena Hess:

It is correct. And unfortunately, as the Parkinson's progressed for some of these people, they couldn't leave their homes. So, that's why. Yeah.

Polly Dawkins:

So, what recommendations do you have for our audience who might not have somebody like you or the jury or the team to come into to an office? What would you recommend or strategies to get?

Serena Hess:

One second. I'm sorry. Well, if the provider can't come into the home, like having an order for the in-home PT would be very helpful. Yeah. Or an in-home nurse, too, in a lot of those companies can do both. So, that would be very helpful. Yeah.

Polly Dawkins:

And you also mentioned telemedicine earlier.

Serena Hess:

Yes.



Polly Dawkins:

That's a good,

Serena Hess:

Telemedicine is huge. If that is something that you were able to do and your loved one with Parkinson's is comfortable to do. So, a lot of the, a lot of the stuff, if you have a good connection, the tremors, the rigidity, all of that can now be seen on screen. So, that would be very helpful.

Polly Dawkins:

Great. Super. Feel free to take some more water there.

Serena Hess:

Sorry. Yeah. I didn't know why I was having it. My allergies are really bad. Give me one.

Polly Dawkins:

No problem. Yeah. And I will. In the meantime, I'll ask folks if you all have questions for arena here; please ask your more universal questions, not, not maybe, the specific ones. And we'll try to get to those. I know you're all Charlie.

Melani Dizon:

Sorry, I have some.

Polly Dawkins:

Oh, great.

Melani Dizon:

Super, super.

Polly Dawkins:

Let's wait for Serena to get a drink here.

Melani Dizon:

Yeah.



Polly Dawkins:

And that's the voice of our beloved Mel in the background. Hi,

Melani Dizon:

I'm furiously adding in the back. This is, we have so many, this is one of those things where I'm like, oh my gosh, we have so many resources that are answering these questions, which is super helpful. I'm glad that we have them. Yeah. Somebody said, oh, this, I'm just going to ask about this particular over-the-counter drug. They said our M D S recommended lithium orate over the counter to reduce anxiety and depression. My person with Parkinson's started with five milligrams, is now 10 milligrams and sees lots of positive differences. So, that's good. I need it, okay? My husband has already had the advanced symptoms that you described, and she's wondering what symptoms occur beyond the ones that, I guess, maybe we're all used to hearing as advanced symptoms, that came in a couple of times.

Polly Dawkins:

So, things that are really much more advanced Parkinson's. Yeah. And somebody else will ask how to deal with the daily grieving experienced. And I think we're going to get into the deep, deep, into grieving and loss in a future session, aren't we?

Melani Dizon:

Yes, definitely.

Polly Dawkins:

Great. So, Serena,

Serena Hess:

I'm back. Sorry. Good. Yeah, no

Polly Dawkins:

Problem. No problem. Tell us, let's, let's dive. We've got a number of questions about really much more advanced Parkinson's for people who've been living with Parkinson's for much longer. Tell us a little bit more about those symptoms and what are our care.

Serena Hess:

Well, I know that everyone, I haven't really, well, I was having my coughing fit. I did look at some of the chat questions, and yes, I did visit some patients who were bed-bound. Okay. And



so, I think that involves a higher level of things that you might need at home. Right. And so that patient, for instance, had a Hoyer lift. I don't know if that's a term that some of you are familiar with, but it's an actual machine that goes over the bed that then helps get the patient in and out of bed into their wheelchair so they can do their activities of daily living, that type of stuff. So, yeah, I did see some of those patients, too.

Polly Dawkins:

What other late later-stage symptoms and later-stage topics that should we be thinking about for our audience here who might have been living with Parkinson's for 20-plus years?

Serena Hess:

Yeah. So, I mean, unfortunately, some of it is the dementia stuff, right? And just being cognizant of that that can happen. And also, some, you know, you might've gone through your whole Parkinson's experience with no hallucinations or delusions, but all of a sudden, those can start popping up, too.

Polly Dawkins:

Yeah. So, when is it a good idea for a care partner to get involved when they see when they start to notice those symptoms? Do you mean, like, talk to them about it? Could you get a little muddled there? Oh,

Serena Hess:

I'm sorry. Do you mean when it is time to talk to their-

Polly Dawkins:

The time to talk with a movement disorder, neurologist, or provider? When you start experiencing some much more advanced cognitive or behavioral symptoms,

Serena Hess:

I think as soon as possible,

Serena Hess:

If you start experiencing those, because then, as we talked about before, with those drugs, the donepezil, and the rivastigmine, they're not necessarily going to get some of that cognition back, but hopefully, they can kind of stop the person where they're at to at least retain some of that cognition for a little bit longer. So, if you start noticing those things, or as the caregiver, you might not notice those things, but your adult children might, you know, because they see



their parents less than you do every day. So, just to be like, oh, you know, my son said that Dad seems to, you know, be forgetting a lot, or Dad said some really strange things to me that I'd never heard before. Kind of take those to heart and then just start looking at that. And if it keeps happening over and over again, write it down in your symptom log and bring it up at your next visit. Yeah.

Polly Dawkins:

And we started talking a little bit about hallucinations. Again, we're going to go a deep dive in a future session about that. But somebody has a question about it. Do you change doses? Should a person change their routine with carbidopa-levodopa if they start experiencing hallucinations? Or is there a difference?

Serena Hess:

That is up to that person's provider. Okay. But what is the caregiver's role in reporting it, right? Because there are so many times it was interesting, I think when you are invited into someone's house as I was as a nurse, which was a very special relationship that I had with my patients and their caregivers, they open up a little bit more, right? And so, I think sometimes it's hard when you're going into a provider's office, and you're like, oh, I only have 20 minutes. I need to tell them this, this, and this. Right? Sometimes, we don't disclose everything, but if you have it written down in a log, you can be like, here's what's happening.

Polly Dawkins:

Yeah. What?

Serena Hess:

Do you think? Do we need a change in this? Do we need a change in that? And honestly, I cannot tell you how helpful of a tool that is for providers. So, it really is, and for you, I mean, as a caregiver, you have so much gone on. Like, are you really going to remember everything that happened over the past three months? Nope. But if you write it down, you can, you know, then it's out of sight, out of mind. You write it down, and then you can just hand them the list. So

Polly Dawkins:

Yeah. It draws attention to the role of a pharmacist on the team.

Serena Hess:

Yeah. You mean, like, should we have had a pharmacist on the team or?

Polly Dawkins:



Well, just in general with, as our community is assembling teams and have, you know, changing people on their care team. Oh, sure.

Serena Hess:

Yeah. Pharmacists, they're great. Yeah. You know, I think it's,

Polly Dawkins:

And review meds and look at contraindications.

Serena Hess:

Yeah.

Polly Dawkins:

Yeah. It's

Serena Hess:

Really important. I think, regardless of whether we have Parkinson's or not, as we age, I can't tell you how beneficial it is to have a good relationship with your pharmacist. Yeah. You, yeah. I mean, especially in this day and age, where sometimes now it's hard because there's drug shortages, right? But if you have a good relationship with your pharmacist, because there's, you know, there's going to be black box warnings on everything. So, if you have a good relationship with your pharmacist to be like, all right, well, they just prescribed this, what do you think of that? You know, and then you can have a real honest conversation with them, which is great.

Polly Dawkins:

Yeah. And I know we're always trying to go to, do you go to this place? Because There's a little bit cheaper deal and this person starts.

Serena Hess:

Giving

Polly Dawkins:

You an incentive to move your meds, and you're, you know, you're trying to do all that. But to have somebody overseeing the whole,

Serena Hess:



It's huge. It's really huge. Yeah.

Polly Dawkins:

Great. A question from a care partner who's earlier in the Parkinson's process indicates we're 14 months into this Parkinson's diagnosis. When do meds start?

Serena Hess:

That depends on the person with Parkinson's symptoms. Right? I, I from, I did not see many people early on. I was seeing the people later on, but I think it's great that the person has the diagnosis. And then again, I think once you're diagnosed, it's never too early to find a movement disorder specialist that you really like, that you trust. And then again, just keeping track of the logs of the symptoms of what's going on. And then that can be a wonderful conversation between your person with Parkinson's, you as the care partner and the provider, and just asking, what does this look like? It is okay to ask those questions, and sometimes, if you don't ask the provider the questions, they're not just going to give you the answers magically. Right. But it is okay to ask the question, what do the next five years look like for us in your mind? And then they can have that conversation with you if that's what you want.

Polly Dawkins:

So, somebody also mentioned that their person with Parkinson's doesn't like it when they reveal what they witness. So, what care partner revealing to the provider, what they witness? How do I how do you handle that?

Serena Hess:

I think you handle that very delicately. And you know, there are certain ways that I witnessed that that's where our licensed clinical social worker came in, you know, very She was just a wonderful, sensitive, quiet, calming person that would have great discussions on how to handle that. Some of it is that, unfortunately, those are conversations that need to happen so you can get the treatment that you need. So, there's that. But also, with the addition of, you know, MyChart and being able to message your providers all the time, sometimes we would have a visit with one of our patients, and then a day later, we would get a whole different message and just being like, I want to let you know, there's all this compulsive stuff going on. I didn't want to talk about it in front of my loved one, but here's what's really going on. So, that's another way to do it through messaging to your provider, too,

Polly Dawkins:

Through the patient portal or,

Serena Hess:



Yeah.

Polly Dawkins:

Somebody also said, I, my person with Parkinson's, don't want me to reveal that they have Parkinson's, so I have to keep that secret. Do you, have you had any experience with that?

Serena Hess:

So, let me get a little bit more clarification on that. Doesn't want to reveal that they have Parkinson's to anyone or to a provider,

Polly Dawkins:

The outside world. To the outside world.

Serena Hess:

Well, you know, I really believe in autonomy. So, if that's what that person wants, then, you know, I think until they are non-safe, then that's what we're at. Right? But then it's important for that care partner to have someone that they can talk to, whether or not it's a, you know, a therapist maybe to just be like, this is what's going on here. This is really bothering me. You know, how can I deal with the fact that right now, we're keeping this big secret? But then I think once that person with Parkinson's starts becoming dangerous to themselves, you know, where maybe they shouldn't be driving anymore. Maybe they keep falling, you know, maybe they're kind of self-medicating with alcohol and/or other things, you know, then unfortunately, that's probably a different conversation that needs to happen between the person with Parkinson's and their care partner and whatever provider they have.

Polly Dawkins:

Yeah. And somebody mentions that you know, you have to make it clear to the loved one that you are both living with Parkinson's or, and you know, that you, as a care partner, your quality-of-life matters, too. And holding it sure does. It's hard.

Serena Hess:

Yeah, it sure does. Yeah.

Polly Dawkins:

Quality of life is important for both of you. Yeah,

Serena Hess:



It really is. It really is. You know, if you're someone's care partner and you can't take care of yourself, then how are you going to be able to take care of someone else? You know, you have to find those moments for yourself on a daily basis, whether it's a walk or a meditation or something, you know, that can help you get through the day because you're still a person with needs, too.

Polly Dawkins:

Yeah.

Serena Hess:

Yeah.

Polly Dawkins:

And I guess there are scenarios where you're keeping it a secret from the outside world, and then people start noticing changes in other people.

Serena Hess:

Yeah, that's for sure. You know, I, although again, since I worked with people who have progressed, right? I do know stories of a lot of, for instance, a few businesspeople, you know, who did not want to share that they had Parkinson's with anyone because they felt it would affect their career and what people thought of them and what have you. But then after a while, when they started missing meetings or saying things, you know, it was, it was hard. So, I think in this day and age, I hope that a diagnosis of Parkinson's or early-stage Parkinson's isn't going to, you know, be a bad thing. So, people will feel more and more comfortable sharing that with the world. Yeah.

Polly Dawkins:

Start to change the stigma around.

Serena Hess:

Yeah, for sure. For sure.

Polly Dawkins:

Yeah.

Serena Hess:

I hope so.



Polly Dawkins:

Yeah. Somebody mentioned to us that they said if I feel the doctor should know some things, and it is not okay with them, with my person with Parkinson's to tell them at a joint meeting, they say you can also mail, use the US mail to contact the doctor. They are realizing that the Dr. May not be able to answer your concerns due to HIPPA. This, the person says, is what I would do if I thought their doctor should know something is mailing because sometimes you don't have the email for the doctor directly.

Serena Hess:

Yeah.

Polly Dawkins:

On the patient portal. So, send, go snail mail.

Serena Hess:

Yeah, for sure. Yeah. Yes, that could work, too.

Polly Dawkins:

Yeah. Other things that you would like us to communicate to our care partner audience today? Serena, other takeaways, other tips about complications and or medications?

Serena Hess:

Yeah, I kind of had a list of things, and let me see. You know, the big takeaway is I think doing a yearly medication reconciliation is really great. Make sure they're not on those fall-risk medications that we had talked about, like Benadryl, Unisom, and Tylenol PM. Anytime your loved one is going to the doctor's office or has an in-home nurse, have them do a sitting and standing blood pressure medication. Because That is the one that will show them whether or not they're having that orthostatic hypotension, and what that means is, you know, you have the top, the systolic number, that number will literally drop 20 points within one minute, and then that bottom number will drop 10 points within one minute. So, I think it's such an easy tool to have your loved one get their hypertension, or their hypotension measured with the sitting and standing. So, just ask for that because a lot of places don't do that. And I would do that every time I went into one of my patient's homes. We would do a sitting and standing. It literally takes one extra minute.

Polly Dawkins:

Yeah. Instead of just sitting, right? Just sitting doesn't reveal.

Serena Hess:

No, you are just sitting. Sure, everyone's blood pressure is going to be good sitting. But then when you have Parkinson's, what happens is you stand, what happens is those neurons in your brain get a little loose, and they can't tell your feet to push that blood back up to your brain. And then that's why your blood pressure drops and that's why you get dizzy, and that's why you fall a lot of times. So, yeah, so just ask for it. Say, I want to see sitting and standing, and that can show you a whole lot of things, actually.

Polly Dawkins:

Are there any other tips that you had, or is that on your list?

Serena Hess:

Let's see, what else was on here? Oh, again, just also realizing that the medications you've been on your whole life might not be applicable to you as, you know, when you were 40. You have been prescribed something, and now you're 75, and you have Parkinson's. Have your movement disorders specialists really taken a look at that list and say, is it really, really important for me to be on lisinopril? Right. You know, or on Lipitor, because, you know, if it's not, then that's two fewer medications you need to take and sort out on Sunday with your partner. Yeah. So, yeah, that's really helpful, too. De-prescribing is a huge thing. I think in the aging population, maybe a lot of people don't take the time to do it. So, that's a really helpful one.

Polly Dawkins:

And is that, is that part of the yearly medication reconciliation that you talked about?

Serena Hess:

Yep, I would do that. Yep. I really would. I think that so many of these things are simple things that could be done that as a caregiver you can ask for, you know, that I think we don't think to ask for, so get a sitting and standing blood pressure for my loved one. Here are the medications that we're on. Do these still look like they should be medications that we're on? You know, and then, oh, here are the symptoms that they have had in the past two weeks. What do you think? You know, a lot of it, I think, probably is, maybe this is my big takeaway. I think what I saw is that a lot of care partners just feel like they don't have a lot of control, right? With this disease progression. But there are some things that you can control, and it's these little simple things that might make your life and your loved one's life a little bit easier and have them be able to be treated with the correct medications. Right,

Polly Dawkins:



Right. Yeah. All right. I'm just looking to see if there's anything else before we bring it to a close. I think we've done our best to answer as many questions as possible in this short time. So, for those of you watching, perhaps you could think about another homework for yourself. We talked about a medication log. Perhaps you could download a medication log that we'll send you a link to and do a bit of recording of what's going on in the medication. Could you also find a person to help you with your medications on a weekly basis? Again, it is not for everyone, but that might be a strategy to help reduce the pill-sorting burden. Also, think about what challenges do you notice about your person with Parkinson's medications. Are they? Are you missing doses?

Polly Dawkins:

Are there things that are no longer working as well? Are we, are you mixing up medications? And what system, in addition to a medication log, what system are you using to stay on top of your medications, your medications, and your person with Parkinson's medications? And as we close today, Serena, we're so glad that you're in this community, and that you offer so much to our community. Thank you for being here. I'm hopeful that when you're done with your program, we can get you back to talk about some of the psychiatric sides of your world and what you're doing.

Serena Hess:

Yeah, it's really important. You know, physical health and mental health with this disease is goes hand in hand. So

Polly Dawkins:

Yeah. Thank you all, and we'll see you on Tuesday. Thank you, Serena. Have

Serena Hess:

A great day. Everyone.

Polly Dawkins:

All. Take care, folks.

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