

Care Partner Training

Session 8: Navigating the Healthcare System, Medicare, Medicaid, and Patient and Care Partner Support in Parkinson's with Sarah Chen, LCSW

Davis Phinney Foundation

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

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

Hello, and welcome everybody to session eight of our Care Partner training program. Once again, I am Polly Dawkins, executive director of the Davis Phinney Foundation, and I am thrilled to welcome our very special guest, Sarah Chen. Hi, Sarah.

Sarah Chen (LCSW, Rush Movement Disorders Clinic):

Hi Polly. Thanks for having me. Super.

Polly Dawkins:

Today, we're going to talk about navigating the healthcare system, Medicare, and patient and care partner support. Let's get started. Welcome, and I would love to introduce you to our audience. Could you tell us a bit about who you are, the role you have played on Dr. Jori Fleischer's research team, and the experience you've had around navigating healthcare systems in general?

Sarah Chen:

Of course. So, like you said, my name is Sarah Chen. I'm a master's prepared, licensed clinical social worker. I've been working at Rush for the past ten years and with our movement disorders clinic, where Dr. Fleischer has worked for almost the past nine years, so I have become pretty familiar with some of the struggles and, you know, unique symptoms and needs of this population. I'm part of a palliative care clinic embedded within our movement disorders clinic at Rush. And I'm also a part of a research project that Dr. Fleischer is in the process of developing. So, I wear several hats. Prior to joining Rush, I worked in a long-term care facility for five years. I know I don't look old enough to have been working for almost 15 years. Still, I bring a lot of experience, specifically working with older adults, their care partners, and people kind of navigating chronic illness. So, it's a pleasure to be here.

Polly Dawkins:

Thank you for your commitment to our community.

Sarah Chen:

Of course, you know, navigating health systems is such a struggle, so it's always, you know, trying to help people figure out how they get their needs met and what the best way to go about doing that is. So, hopefully, today, we can cover a few of those things.

Polly Dawkins:

Oh, let's dive into that a bit. So, when you think about the years of experience you've had working in the Parkinson's community, both with people with Parkinson's and their families and care partners, tell us a bit about some of the biggest challenges that families face as it relates to the healthcare system.

Sarah Chen:

Yeah, you know, some of the bigger challenges can be just even navigating medication and how they manage what can become a pretty complex medication regimen. Navigating changes for as someone's condition changes, it's the care partners are also then navigating how do we adjust to these either new symptoms or new circumstances. You know, managing home safety, how, you know, keep, how can someone stay at home? How do we maintain our house to be safe, or what do we need to think about and if we need to make some modifications, you know, how do we go about getting equipment or, you know, even getting someone to come in and take a look at the house. And even one of the biggest questions or concerns I often hear from people is thinking about then how do we bring in help. How do we know when it's time, or how do we know when it's time to make a transition?

Polly Dawkins:

Wow, those are big topics,

Sarah Chen:

You know.

Polly Dawkins:

In your role, do you handle all of those topics, or do you have other people you call in and lean on to help with some of those topics?

Sarah Chen:

Yeah, I think that often what I end up doing in many kinds of situations, so clinic-based social workers do, is helping people navigate through some of those questions. And, you know, I can help specifically work with families as they think through some of these things. And then I can refer them or know of people in the community of, you know, if you need a home safety evaluation, here are people where we can go, you can connect with, or here's how we think about how much help you might need or when you need it. And here are the resources in the community to begin exploring. So, a lot of it's kind of the groundwork or foundation and then

helping point people in the right direction. So, direct, I am. I am not an expert in knowing how wide your door doorways need to be, but I can help you find someone who can better assess that.

Polly Dawkins:

So that would be maybe an occupational therapist, you'd think?

Sarah Chen:

Exactly. Yeah. And there are many that specialize in doing home safety evaluations, and that you can get it even covered by the insurance. And so, we can, you know, that's where a social worker can help you navigate through some of that. Even the clinic nurses, as they do this, are become more and more familiar with it as well. So

Polly Dawkins:

To review, so the things you talked about that the challenges that you see is medication management, navigating care partner changing roles or the changing roles as a care partner, home safety, how to get medical equipment and devices, and then how to transition to long-term care or when to transition to long-term care. So, as you think about those things, are there any stories that, from your experience that, jump out to you in terms of those, somebody who had a particular challenge that you had to navigate through or on any of those topics?

Sarah Chen:

Yeah, I think about, you know, I think about even something that might feel as simple as getting durable medical equipment. Like we, you know, maybe someone is starting to need a walker or a wheelchair, and they're not sure where to start, so they've bought something out of pocket or they, you know, got a piece of equipment. But then, in talking with us as part of the team, we realized they got a basic wheelchair, which is covered by the insurance and potentially can be a good fit. But, you know, really, they wanted the wheelchair to be able to get in and out of the trunk to take in the community. The standard heavy wheelchair is about 60 pounds, and it is not really feasible for the care partner to be lugged in and out of a trunk. And so, it's some of those instances where we can help guide families to say, what is it that you're really looking for?

Like, or then figure out what's the best equipment, or do you want to try like a tub? Bench might be ideal in the shower, but we don't know exactly if it's going to work for you or your setup because everyone's setup is so different. So, maybe let's borrow something from a nurse's lending closet. Here's where you could find a nurse's lending closet in your community, borrow something, see if it works, you know, and then if it doesn't, okay, so you just borrowed something, we take it back, and we try something else versus, you know, spending the money to purchase something and then have it not work. So, you know, thinking equipment feels like it would be like a simpler thing, but can, you know, a little bit of a conversation or some planning

on the backend be helpful? Even with medication management, as someone's symptoms may increase or, you know, they need their medication more frequently, well then how do we decide we're not, we as humans, we're not designed to be able to, you know, have an alarm system internally to know every three hours to remember to take your pills. Hence, you know what resources are available, how they are, and how we can use an alarm medication dispenser to set that up.

Or how can we set alarms on the phone or what resources can we utilize so that the care partner isn't, you know, owning or having to keep track of everything all on their own or have someone missing doses regularly? So, it's some of those conversations.

Polly Dawkins:

So, all of these things that you're talking about really seem like they impact a person and a care partner's quality of life.

Sarah Chen:

They really do. They really do.

Polly Dawkins:

Can you talk about that a little bit and the connection?

Sarah Chen:

Yeah. You know, I think one of the things is that quality of life can have an impact, like physical changes that can impact quality of life. There can also be kind of this perceived idea that quality of life has changed that because I have this new thing that's affecting me, it means I can't do X, Y, Z. And often, you know, in the palliative care clinic where I work at Rush, we're spending a lot of time thinking about how can we maximize quality of life? And what might feel like small changes to address symptoms can really have a bigger impact than, you know, it might seem on their own. So, if someone's in, you know, being really bothered by constipation or they're losing weight, or we're struggling at a certain time of day, you know, thinking through or troubleshooting some of those specific things can really then have a much larger impact because maybe we're not struggling so much with constipation. We get a bowel, a better bowel regimen, well then maybe we're feeling better, and we're able, our medication works better, we're able to go get out and about, and we're able to do more because we're feeling better.

And, you know, if you thought about just attributing like, oh, it's just my constipation, like it really can have a larger impact, and don't mean to focus so much on constipation, but it's something that patients often struggle with. Their families struggle with it, and they don't always connect it to the illness. You know, palliative care can really be helpful to families, even thinking about what comes next. How do we anticipate, or how do we know what to expect? And that, again, can kind of relate to quality of life, of thinking about, well, what do we need?

Or when do we bring, when do we decide it's time to do something different? And if you have a little better idea of the kind of what to expect going forward, it can help. It can sometimes help patients and families then make a decision about, okay, if I sort of anticipate this thing maybe then coming down the road, we don't exactly know when or what it will look like, but this is kind of the progression of how things happen. If that's maybe what we might anticipate seeing next, well then how will we? How can we be a little more proactive and not be responding or reacting to the crisis? Maybe we can be a little more proactive and feel like they have a little more control over what's to come or how they respond.

Polly Dawkins:

You know, you bring up palliative care. I was going to ask you this a little bit later, but I think it's important to help our audience understand what palliative care is and how does it differentiates from hospice care.

Sarah Chen:

That is a great question. For so many people, it can get lumped together, and they really are two distinct things. Palliative care is an overarching umbrella that, as I mentioned, focuses on quality of life—maximizing understanding of someone's wishes and preferences for care. And then helping someone think through whether a treatment or decision kind of aligns with those wishes and preferences. It can help with providing anticipatory some of that anticipatory guidance. Hospice is a small piece of palliative care that's focused on the end of life and maximizing someone's quality of life at the end of life. So, focusing on comfort is a big piece. Hospice is a benefit. Well, palliative care and hospice are a benefit to patients and their families. It can really have a big impact on families, care partners as well as patients. Hospice, you do have to have a physician certify that you would have six months or less to live.

That being said, no one has a crystal ball. You know, they're looking at symptoms. Would that trajectory look like that? But we have a lot of folks on PA on hospice care that, with a little TLC, they do so well on hospice and end up graduating back off of hospice because they've done so phenomenally well. So, you know, it can be a really helpful benefit. And you know, sometimes people think, like, when do we start palliative care? Palliative care could start at the time of a diagnosis because there could be a lot of adjustments of sort of understanding the diagnosis, understanding what this means, understanding the progression of symptoms, and responding to that. That's all within like a palliative care philosophy. So, starting, you know, it's all individual in what people feel comfortable with, but potentially starting it earlier than you might think at face value.

Polly Dawkins:

Yeah. If you don't have something like that in, you know, you don't have a rush clinic near you, or you're not near a large institution, how do you imagine that somebody in our audience could piece together a palliative care approach for them, for themselves?

Sarah Chen:

Yeah, that's the question. There's home-based palliative care. So, a lot of organizations will provide both hospice and palliative care. So, don't be scared off if hospice isn't in the name. Palliative care is also a part of what they offer, where it can, you know, it's in the community, it can come to your home. As well as you can also find palliative care providers at the International Neuro Palliative Care Society. You can look up physicians who are palliative care trained, as well as the American Academy of Hospice and Palliative Care providers. I can't quite remember the acronym, but I can get it to me, and we'll make sure it's in the resources at the end. But there are ways that you can find providers all over the country, and even your primary care physician or your local neurologist may be able to sit, you know, recommend a palliative care provider in the community as well.

Polly Dawkins:

And the big question many people will probably ask is if this is covered.

Sarah Chen:

Oh yeah. As soon as you started, I was like, I didn't mention that. Yes, it's covered. It's covered by your insurance. Hospice and palliative care are covered by Medicare and the majority of commercial and state-funded programs. You might need a referral potentially from your provider, at least for hospice care, for sure. In palliative care, you can often kind of refer yourself in. But it would be covered by the insurance the same way other medical appointments are covered.

Polly Dawkins:

Super. Thank you for that. Let's go back to understanding the healthcare system in the United States. We have many people watching from outside of the United States, but we'll be focusing on sort of the healthcare system here. Can you help us understand a couple of definitions? So, for example, what is In-Home Care?

Sarah Chen:

Sure. So, in In-Home Care, I think some of the struggle is that so many of these things go by lots of different names. In-home care is often private duty caregivers who then come from a state program. So, depending on your state, it's called different things, but often under the umbrella of maybe like a Department of Aging or Department of Family Services or through a private pay agency where you're paying for care a certain number of hours, a certain number of days a week, or you found an individual on your own. You're paying that person directly to provide care. If you're a veteran, you also may be eligible for services through the VA and its system of services and support for veterans and spouses of veterans. So, you can also potentially get some in-home help through the VA as well. And this is different from what is called home healthcare.

I didn't come up with names. We should be calling these names something very different. So it's less confusing. Home healthcare is something that is a skilled benefit through the insurance. It's for people who are often either recently been hospitalized and need a little extra support as they're transitioning home from a hospitalization or in a nursing home for rehab. And again, needing help with that transition home or need a tune-up. I've kind of been at home; maybe they had things that have just declined a little bit. It was winter, and we were not getting out as much, so we needed some additional physical and occupational speech therapy, a nurse who could come to the home, and potentially a bath aid. And so, that's ordered by a physician. It's time-limited and covered by the insurance, which is why you want the physician's order and covered by Medicare, commercial insurance, and most state-funded programs. It's time-limited. It's usually six to eight weeks, and they'll come a couple of times a week depending on how someone is making progress. And sort of what the needs are. But unfortunately, we know that someone would benefit from the kind of ongoing physical therapy to help maintain; unfortunately, the programs aren't designed that way. So, we usually have to have a break in services for about three months before we can ask for a new order for home health to come back out. Does that make sense? Yeah, yeah. Clear as mud.

Polly Dawkins:

Well, yes, because you've got in-Home Care and then you've got Home Healthcare In-Home Care, it sounds like you can take advantage of state programs or the VA, and those might be covered.

Sarah Chen:

Yes.

Polly Dawkins:

Or private pay, where you're actually paying somebody yourself.

Sarah Chen:

Yes. The distinction, which I was not clear about, is that when you have an in-home caregiver, they're probably helping you with some of the self-care things around the house day to day to help you continue to be functioning as well as you can and helping, you're like help your household continue to run, run. And so, that can look like a whole different, a whole bunch of different things depending on what your needs are. It might be that you have someone come in in the morning to help you get up and dressed and, like, going for the day because mornings are a little bit more difficult or, and maybe they're helping you know, run the vacuum, change the sheets you know, get a meal together. You kind of can determine what it is that you need help with based on kind of a whole myriad of factors, what's going on.

Meanwhile, that's the home in-home care they're doing, helping with self-care and things around the house. At the same time, home healthcare is more rehabilitation. They're focusing

on getting you moving, helping with, you know, you're walking with your strength, with your mobility, maybe hand using your hands, things like that.

Polly Dawkins:

Yeah. So, it sounds like the in-home Care option; if you have that estate program that's covered or you have the ability to pay for it, that could be really helpful for Care Partners. Yes. Sounds like daily tasks could be taken off the care partner's shoulders.

Sarah Chen:

It can be a huge help. Because you know, from my experience talking to Care Partners, they end up taking on you as a care partner end up kind of gradually taking on more and more of the household tasks of, of everything that goes into running a house from, you know, mowing the front lawn to paying all the bills to grocery shopping and meal preparation and the list goes on and on like that is just the tip of the iceberg. And that leaves very little time for care partners for them to, you know, go to their own doctor's appointments, or have a social life or do anything that's important to them as well. And not to mention if, as a care partner, you're also trying to work or raise a child or, you know, anything else like that. So, in-home help, this private duty caregiver that can come in can really take a lot off of or shift some of the things off of a caregiver's plate onto a hired caregiver.

That then allows the family caregiver time to go to work and not be worried that, you know, what's my loved one? What's going on with my loved one at home while I'm at work? Or I joke about it in the clinic, but I think it's very much a reality kind of the supermarket dash that, like, how much time can I leave my loved one home alone? Okay, I've got 45 minutes to go to the grocery store. Like, how fast can I get through the aisles to get what I need and get home so that I know that my loved one is still okay? Well, what would it be like if you had a caregiver there and you could go to the grocery store, like run a bunch of errands, and not be worried that you're going to come home to find that your loved one got into some mischief and you know, needed to go to the bathroom and what ensued after that? You know, we don't; I don't want that for anyone. So

Polly Dawkins:

Would you remind us again of the names of the state agencies that somebody might look at to see if those are available for them?

Sarah Chen:

So, a great resource is what's called the Elder Care Locator. It's through the federal government. You can Google the Elder Care locator and search by your zip code, and it's going to tell you the name of the program for your specific state. So, then, and it will tell you who to contact. So, for most of the aging programs, it's probably going to be an area agency on aging, and it will tell you the number and who to call. And you can talk to an intake coordinator there

and say, I'm interested in learning about caregiver programs. Does my state offer any? Do I or my loved one qualify? Tell me more. And if you don't qualify, do you have a list of agencies where I could contact to potentially find a private pay caregiver? It would be a great place to start.

Polly Dawkins:

And qualify would be based on your income.

Sarah Chen:

Yes. Often, it's based on income assets, and they are also, for many of the programs, they're looking at whether you physically need the help so that someone who maybe would just like the help but doesn't necessarily need the help may not qualify. I don't anticipate that's anyone in this audience, but they are looking at it physically. Does someone need assistance as well?

Polly Dawkins:

You know how much Medicare would cover. So, if you don't qualify for the low-income program, do you know what Medicare covers for In-Home Care?

Sarah Chen:

Well, that's a really great common question we get, Polly. Medicare does not cover In-Home Care. The Medicare program, the health insurance that many seniors 65 and over or people with disabilities are on, is designed to be a medical insurance. Still, unfortunately, it does not cover in-home care. So, that's why we end up with this kind of piece-together program and why it is such a challenge for people to piece together health in the community. It's really messy to figure out what you qualify for in your program or in your area and what that's called and doesn't. So, I just want to affirm for everyone who's listening on this call that it is a challenge. Sounds like it's so hard to know what you qualify for and how you find it.

Polly Dawkins:

You have a question from William. He asks, can a client have both home health care and in-home care at the same time?

Sarah Chen:

They absolutely can. Yes. That's a great question. Super.

Polly Dawkins:

Alright, well I could think I could spend the next half hour. We only have another half hour together on these topics, but there are so many others that we'd like to touch on. Please tell us a little about what we've discussed in-home care. We've talked about home healthcare. Tell us

a little bit about sort of the next step, which is long-term care or moving into assisted living, and what does that mean when some, when would somebody think about that?

Sarah Chen:

Yeah, so there's long-term care; we're going to talk about this. There are a couple of different levels. Assisted living is kind of where you have an apartment, and you are still probably able to get yourself dressed and get yourself down to a dining room. You might have a studio or one-bedroom kind of apartment, but you're going to get help with some specific tasks. Generally, those would be meals. Whether it's two or three meals a day in the ADA common dining room, you'll get help with a shower a couple of times a week, and you'll get help with housekeeping, and then you may be able to kind of a la carte purchase some additional help. So, that might be help from the assisted living facility nurse who sets up your pill box every week or medication reminders that one of the aides in the facility then comes and knocks on your door and says, Hey Sarah, it's time for you to take your pills.

You might get escorts to activities like every facility is a little different. They have their kind of a la carte services, but you're still, someone's still generally fairly independent, but they don't; there are a lot of reasons why someone may choose to stay in their home or go into long-term care. There is no right or wrong way. Everyone's situation is so different, and everyone feels very differently about that decision as well. So, off the top, I want to say that there is no way to do this. And as you sort of think through, individuals want to think about, you know, again, what's most important to them; I hear from folks that say like, I don't want to be a burden to x, Y, z. My kids, my spouse, my, you know, my neighbors, whoever I'm going to, you know, I don't want to have the responsibility to take care of this, this house anymore when it's really hard for me to do it on my own.

So, I'm going to make a move into an assisted living facility where I live alone, and it's really lonely. I miss community, and I miss people to talk to at my meals. You know, I don't want to be; I don't want to be home alone all the time. Great. Then, finding a community that's going to be a good fit for them, you know, might make the most sense for other people. They say, I, my grandma was in a facility, you know, I never, I want to be in a facility. Okay, so then how do we try to make your current situation as safe and supported as possible? So, when people think about assisted living, you know, wanting to make sure that it, there's it, you know, is faith important to them or a specific religion is dietary options most important. Our activities most important are important that the facility has different levels of care so that if you need more care in the future, you can stay within the same community but kind of transition between levels of care or you want nothing to do with that and you just want to be in an assisted living?

It's so nuanced for everyone's situation. The one thing to think about with assisted living is that there isn't someone with you all the time. Like you're in your own space, your own apartment, there's someone there 24 hours a day. It's usually kind of like a certified nursing assistant. They don't usually have nurses there 24 hours a day. So, if something happens in an emergency, you'll have a way to call for help from someone in the building, but most likely, that means

they're going to be going to the emergency room to be evaluated. It's, and if someone's having more trouble with mobility or more difficulty with some of those self-care tasks, getting up, getting dressed, getting down to a dining room, you may have to make a move to a higher level of care or bring in more help to stay where you are. So, it can be a great place for people for a while, but for many people, we're starting to think about when we need more care again or when we need to make another transition.

Polly Dawkins:

And are there any insurance programs that pay for that level of assisted living? Is it long-term?

Sarah Chen:

I keep forgetting to mention this. Yes, long term, if you have a long-term care insurance policy, depending on the way your policy is written, it may cover assisted living or a certain amount of the cost of assisted living per day. Medicare does not pay for assisted living, and usually, state-supported health insurance programs in Illinois are called Medicaid does not cover assisted living. It covers another level of care that's similar to assisted living, but each state is so different. Assisted living is licensed, and nursing homes are licensed state by state. So, the rules look a little different in each state, and what qualifies for support looks a little different.

Polly Dawkins:

And Donna asks us, "Is there anything that the VA covers or can help with this level of transition to assisted living or-?"

Sarah Chen:

So that's a great question, and I am not certain about if the VA covers assisted living. I know that the VA does provide support for nursing homes. But if you want to know definitively, you can call the caregiver support line that the VA has set up. And they would be able to, that's where you can apply for services through the VA or determine if your loved one is eligible for services and kind of start that process. They can also provide resources about what is in the VA system for resources and support and kind of what programs so they could answer if the VA covers assisted living.

Polly Dawkins:

And can you tell us again what?

Sarah Chen:

It's the VA caregiver support line, and Mel can share this again after the presentation. I'll get her the resources, but you can google it. They have a 1-800 number, and they also have a website where you can learn more about their programs.

Polly Dawkins:

Super. So, when we were talking about assisted living, you talked about sort of a continuum of care at the next level after assisted living, if that's not quite enough and you're, you've had in-home care with assisted living, but that's still not quite enough. Tell us a little bit about what the next level is. Is that called skilled nursing?

Sarah Chen:

It's what is that? And so, we would be looking at skilled nursing. There's a nurse that's there 24 hours a day, and they're helping you with a lot more of kind of your self-care tasks. So, some nurses and aides would be available with the kind of a call button system. They'd help you get up, get to the washroom, get dressed; they'd take you down to your meals. The nurses manage all of your medication and come provide the medication when it's prescribed by the physician. And there's a nurse there 24 hours a day. So, in the event that there is a medical need or a medical emergency, the nurses are going to be there to evaluate you. Now, that doesn't necessarily mean you're not going to need to go to the emergency room to be further evaluated. Because a skilled nursing facility is, does not have, is not equipped in the way a hospital is, but at least you're going to have a nurse that's going to be able to evaluate and kind of keep a better idea on a better idea.

You know, gauge what the need might be, and they can catch some of the things earlier. So, you know, urinary tract infections, I imagine Dr. Fleischer has talked about, are, you know, can be really problematic for our population of folks. If we can catch them early and treat them early, you know, blood work, urine tests, and things like that can be done in a skilled nursing facility, and the physician can prescribe medication. So, we might be able to avoid hospitalization in that way. Yeah, skilled nursing facilities are covered by many state insurance programs. Medicare does not cover long-term stays in a nursing home. Medicare will cover a short-term stay, which is considered a rehab stay. So, post-hospitalization, you go, you can go to rehab in a nursing facility and stay for up to a hundred days.

As long as you're meeting the criteria for eligibility, you are not guaranteed a hundred days, but that's the length of benefit. And so, that's what Medicare will cover during the rehab stay or getting physical and occupational therapy and some other services that may be appropriate for you for long-term care in a nursing home; Medicare does not cover that. But as we mentioned earlier, if you have a long-term care insurance policy, that may cover a certain portion each day, depending on how your policy is written. VA benefits do cover long-term stays in certain VA nursing homes or homes that are affiliated with the VA or the state. The state medical insurance programs will also cover long-term care.

Polly Dawkins:

Super, super. Somebody is asking us in the chat if a person can no longer do things for themselves, like getting a snack, turning on the TV or the phone, or basic self-care things, is it time for a higher level of care? And I guess the other question is how do we know when the next time is?

Sarah Chen:

Yeah, that's always a difficult thing to navigate. You know, if someone needs help with things, they're not able to do kind of self-care tasks. So, in this example, kind of getting a snack, turning on the TV light, and things like that, it makes me wonder if they're also needing help with going to the washroom or getting dressed or things like that. And so, you know, that might make me think then Lewy Body Dementia, depending on kind of anyone's situation, do we want to bring in more help at home or expand the amount of help that we have at home? So how do we know how much help we need, thinking about when we need it or like what are the things we need help with? When do we need that help? And then how much help do we need? And we, as we start to think about that, we might realize like, okay, I need help at this particular time of day, but as things start to change or as you notice, like, well, that we started with three or four hours in the morning, but really, I think we need more help.

So, we're going to bring in help that stays longer, or we're going to shift the time. Like my loved one, I, as a spouse, am able to help my loved one in the morning, but I need to be able to go out. So, I'm going to shift the time to the afternoon into the evening. You might play with the amount of time someone has; you have someone coming. But if we're concerned about falls, if we're concerned about safety in the home, if we're concerned that maybe our loved one starts isn't able to get themselves to the washroom or is getting more impulsive or is starting to develop some changes with their thinking and memory that might be a time when we want to reevaluate what is my current situation, how do I need to make some modifications to what that looks like, or do I need to start to explore another level of care?

Polly Dawkins:

Yeah.

Sarah Chen:

I hear the question. It's so hard to know.

Polly Dawkins:

I hear the question from our care partners that oftentimes their person is resistant to anybody else besides them doing. We've talked about that topic with Dr. Fleischer, but maybe you have some insights as well or stories about people who've had to get through that and get through the guilt of that and how successfully transition somebody else in

Sarah Chen:

It's so hard. I want to say that at the top, it is such a challenge because you want to honor your loved one's preferences and the guilt that you mentioned that like when people feel like they should be able to do it, they should be able to do it on their own. In a nursing home, in a hospital, there are shifts of people that provide the care. And the ho and the hospital where I

work, they work three shifts, and so, some as a care partner, you're not getting any break. You know, you can't; they wouldn't ask a nurse at the hospital to work, I don't know, 24/7 for the next number of years and expect that that nurse is going to be able to keep it up. The nurse would be able to hack it. It's so much. And so, we think about bringing in, like when we think about bringing in help with just having a conversation this week, Nope, today's Monday.

So last week, with a family that was saying, you know, how do I, my husband doesn't want help, or I feel guilty bringing it in or how do I, he doesn't really need it's, but you as a care partner need it. So, we can frame it as I need help; I need a little bit of help. I've got a lot on my plate right now. And so, I would want, I'd like to try to have someone come in so as a, to give myself a little bit of a, you know, allow me to attend to some of the other things that I need to take care of. So, sometimes, framing it as the caregiver is coming, the like outside caregiver is coming to help the family caregiver, versus I'm bringing in outside help to help you as my loved one with a neurodegenerative dis illness.

Sometimes, that can make people more receptive to having care. We also think about trying to do it a little bit earlier than maybe you when you think you need it. Because often, we realize we're like in the pot of boiling water, but you didn't get thrown in the pot when it was boiling. You like turned it up, and then it's you; it got warmer and warmer and warmer and then boiled. And so, we don't realize like how much we're doing until we're like on fire—so, trying to bring it in a little earlier when things are calmer, when, you know, we recognize that there's going to be an adjustment when we have a little more capacity to tolerate. Like this person is going to do things differently, that's going to be; I'm going to have to get used to having a different person in the house while uncomfortable bringing it in a little bit earlier can help because then when we really need it or you've needed it all along, but like when there's been a crisis or something, we've already got the help, and that's not another layer of things you're trying to figure out.

Polly Dawkins:

That's a great, that's a great point. Susan asks us, “What about training for me as a care partner? Would an occupational therapist help me learn how to get my person with Parkinson's dressed and showered and all of those things?”

Sarah Chen:

They would; that's where home health could be really helpful. They're coming into your house and can help work with you as a care partner. So, even physical therapy can help teach you how to transfer—getting someone from one seated situation, like getting them to bed or getting them in and out of the car or something like that. The physical therapist can work with you, and then occupational therapy can, exactly. Like Susan was saying, show you how to give them a shower, get them dressed, and do another kind of tasks that you're needing help with. Or maybe you had that a couple of years ago; your loved one was hospitalized and did a little bit of rehab, and you got a little bit in rehab, but your loved one situation has changed in the last couple of years, and they're not able to help you in the same way that they used to. You can

have home health come again and get just like a re refresher. Reeducation is a refresher. Exactly. Of like, okay, here's where we stand now. How do I do it? How do I do it this way?

Polly Dawkins:

We are also asked the question what if I don't need care every week? I need it as needed so I can go to an appointment and do it. Is it possible to set up care on an ad hoc basis?

Sarah Chen:

It's, it can be. So, here are a few things I think about with that. Going through an agency since COVID has become a little bit more of a challenge because many, not all, but many of the agencies have, like, say, we need you to commit to a certain number of hours, a certain number of days. In order for our caregivers to come if you have us on a routine basis, otherwise we can't necessarily guarantee we'll be able to provide the care. Now, that's not all of them. So, I would certainly, if there are agencies, you've in your area, call and ask and see if they can help accommodate. Another way to find care might be through word of mouth. So, like your neighbor had a caregiver that came and helped them, and they loved them. They thought they were great after they had had surgery; they didn't need them anymore, but they would recommend them.

So maybe you call that person's caregiver and say, hey, would you be like occasionally, a couple of times a month, I need a little bit of help. Would you be willing to, you know, come sit with my loved one so I can go to my doctor's appointment or go to lunch with my girlfriends or go to my like fam another young family member's grandchild, you know, some kind of important event I want to be able to participate in? You see if the caregiver that caregiver's available faith community is really a great way to find kind of word-of-mouth caregivers as well. You might not know that individual personally, but personally, you know, you know, someone else in the community who knows them. Other social connections are networks in the community like well or other family or friends like your other; your adult child has a friend whose loved one has, you know, your cousin's niece, whatever.

Those are great ways to find people and their connection to you. You wouldn't believe the different ways people find these caregivers them, but it can help people feel more comfortable about bringing someone in. Well, they know someone that I know that person can vouch for them. I feel more comfortable, and those people can tend to be more flexible. So, exactly to the point, like this way you have, you get to find a couple of people that way, you know, if the first one's not available, reach out to the other one. You can even ask them, do you know other people? If you're not available, is there anyone else that you might recommend that I reach out to? Because it's important people get out.

Polly Dawkins:

It's really important to take care of your own healthcare issues or your social needs. Pat asks, and they say it sounds like memory care memory is more like help for general cognitive challenges. Could you define what memory care realistically is?

Sarah Chen:

Yes. Memory care can either be offered in assisted living, so there are many assisted living memory care facilities or kind of areas memory care can also be offered in skilled nursing. So, memory care means, or is intended to mean, that there's additional support and training by the staff to recognize how changes in thinking and memory can impact someone's behavior or how we approach someone to, you know, invite them to a meal or invite them to an activity or get them to, you know, take a shower. So, we can, that being said, memory care is kind of a general sort of approach to memory. So, or, or changes in thinking and memory. There isn't always the nuance of Alzheimer's disease dementia versus Parkinson's disease dementia and kind of, so you're probably not; if you find it's a unicorn, and, like, spread the word.

There are not a lot of memory care facilities that are specific for Parkinson's disease dementia or, like its cousin, Lewy body dementia. But that being said, if you find one that you know, you go, your tour, you like the staff, you like the facility, you like the way that you know, the nurses and aides respond that they're consistent, you get a good feeling. You do your research, then you can; you, as the expert of your loved one, can train them to understand the specific situation and needs of your loved one. So, I would say that there are a lot of resources out there that you can provide a facility and say, here's my loved one's individual situation. Here's some more reading about kind of the broader type of memory changes that they're experiencing, and work with them to educate them specifically on your needs. Great.

Polly Dawkins:

Tracy asks us a question, and I'm sure others are thinking the same thing. Who can you talk to help with these decisions? You know, who are these people who help families navigate this system?

Sarah Chen:

Yeah. There are a lot of different types of people who can help you think it through. Social workers like me may be embedded in your physician's clinic. So, I'm part of the movement disorders clinic at Rush, but there's a network of social workers across the hospital system in primary care and other specialties that are available. But if you're not at, like, I recognize I'm in an academic center. If you're not at an academic center, there are lots of social workers in the community. So, as I talked to mentioned earlier, the area agencies on aging, kind of your senior centers, the different senior kinds of state programs are full of social workers. You can get connected to social workers or geriatricians that way. The local community hospital likely has a social worker, the senior center in your area. They will probably have a social worker, or they'll be able to recommend who else to talk to.

You can talk to elder care managers who you might have. Some of them are a fee, but they can help you think through or kind of come into the situation, get a better handle on kind of what's going on, and help you kind of think through some of these things as well. There are social workers who are embedded in community-based palliative care programs. There are social workers who are connected to the home that physician-ordered home health programs. They have social workers as well. You can find a therapist who might be a social worker. Many mental health professionals happen to also be social workers. And while you may be seeing them for a therapy need related to kind of mental health or the responsibility of being a care partner, they also are social workers. And if they are not able to, they may also be able to say, here, I know this person is connected to this agency. Why don't you reach out to them? So, they're we're, we're in disguise all over. It's kind of just trying to find us. And so, hopefully, that gives you some ideas. The VA, too, if you're connected to the VAT, VA has social workers embedded as well. So, I ask yeah,

Polly Dawkins:

If you live where there's a regional or independent Parkinson's organization, oftentimes, they'll have social workers on staff who really understand Parkinson's.

Sarah Chen:

Yes.

Polly Dawkins:

It can connect you to resources in your community as well. Yeah. The larger Parkinson's organizations have finders, locators for social workers as well,

Sarah Chen:

Some of the larger Parkinson's organizations have like staff in particular regions as well. So, again, it's not perfect, but there are ways that some of those larger organizations can still try to help connect you on a more local level.

Polly Dawkins:

Yeah. Super. This hour has flown by. Is there anything, Sarah, that you were hoping we'd touch on that we didn't get to today that would be a takeaway for our community or

Sarah Chen:

I wish we had more time because I think we could talk about this for so long. There are lots. I'll share some of these with you guys so that you can spread the word. There's also, if you want to learn more, there are other resources that you can learn more about specific things. So, International Neuro Palliative Care Society, if you want to learn more about palliative care, you know, finding a specific thing, you can learn more about resources and watch recorded



webinars and things like this. There are so many of these things out there; I know it's hard to find them or find more resources. But I recorded one that I'll share as well, just piecing together community resources that are also available on the International Neuro Palliative Care website. It just launched. So, I want to kind of give you a little more about how you navigate community resources.

Polly Dawkins:

Wonderful. Well, once again, thank you so much for your work in this community and for sharing it with us. Sarah, thank you so much for being here. Audience, thank you for tuning in today, and we will see you back on Friday. Thank you.

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