



**The Victory Summit® Virtual Event: Care Partners
How Occupational Therapy Can Help You and Your Loved One Live Well**

Recorded on November 13, 2021

Davis Phinney Foundation

Polly Dawkins (Executive Director, Davis Phinney Foundation):

Amber is going to be leading our next session. She's going to start with an incredibly useful presentation on how occupational therapy can help you and your loved one incorporate therapy into your daily practice. And then she's going to move into a presentation. To start, let me tell you a little bit about Amber. Amber is a graduate of Kent State University, and she's a state licensed in Idaho and nationally board certified in occupational therapy. Her primary goal in this work is to always help her clients live their best, most independent lives, whatever that may look like. Amber, you ready to take it away?

Amber Crawford, COTA/L (Occupational Therapy Assistant, Ada Therapy Services, PLLC):

I think so. Can you hear me, okay?

Polly Dawkins:

Perfectly.

Amber Crawford:

Okay. All right. So I'm going to start off. I'm going to go ahead and share my screen. So today I was asked to speak thank you so much. First of all this is my very first time giving a presentation. So I get to do it through zoom, which is a little bit different, but I think it might be better maybe because I don't have to actually see everyone staring back at me. But if I do make any mistakes, just go ahead, and laugh. I won't even know it. So again, my name is Amber Crawford. I am a COTA or a certified occupational therapy assistant. Just a little bit about me. I am from Ohio. I graduated from Kent State, as she said, and I work at a small private outpatient occupational therapy clinic.

It's called ADA therapy services and we see people with a range of neurocognitive disorders, a large population of the people that I see have an autism diagnosis. Some adult ADHD, mild cognitive impairment. And I do see people with Parkinson's from time to time. I have a house full, I have an almost nine year old daughter, Josie, my husband and my husband's grandparents



actually live with us. So I kind of have a unique position, I guess, to speak on the aging process. And then we also have our little puppy Finn there.

So I got into OT. It was kind of fueled by a combination of growing up in a split family. So I grew up with around a dozen grandparents, all of whom I grew up very close with and some of them, I was there as they crossed over. And I also worked as a nursing assistant for about a decade. And during that time I worked in long-term care, skilled care, acute care, all kinds of different facilities, memory care units. And within that, I really got to have a front seat to not only the aging process, but the aging process as it looks from a care partners point of view. And I just kind of developed a passion for being able to help people carry on with as much of their independence as they could. So I guess we'll kind of get started in, I don't know how many of you are aware, but OT, the most common question that we get is, well, what are you gonna do for me?

I'm too old to have a job, or I just retired. I don't want another job. We actually don't have anything to do with the employment field. However, if you need a job and that's something that's meaningful to you, we are more than happy to help you with making a resume or applying. But what occupational therapy really means is any meaningful activity. So it's very broad. And whenever you put that together with the word therapy, then we get the healing of participation in meaningful activity. So as you can imagine, that kind of spreads out across the board and it's intentionally that way because an OT, we are very aware that every person is going to have different goals and different things are important to them. And if it's not important to you, we're not going to worry about it. Let's talk about what some meaningful activities are.

So if you think to yourself, is it meaningful for you to get up and get dressed every day? Probably. Right. Is it meaningful to you to go fishing on Saturdays? I can tell you, my husband would say yes, doing your laundry, standing up off of the couch, being able to make dinner, going to church. All of these things come in and we see them as this is what makes you functional and OT, we are based off of the idea that in order for a person to live a fulfilled life, that they also need to feel purposeful. So if you think about that in your own life, when do you feel the best? It's usually after you've done something that made you feel some sense of accomplishment or some source of purpose. So today I'm going to cover how OT can be helpful, not only to our patients who have Parkinson's, but also to the loved ones that are taking care of them.

Again, I see this as kind of one of the most important parts of my job is helping the people that are taking care of my patients. So we're going to touch on a few different topics. We're going to talk about home evaluations, adaptive equipment and some simple modifications in your environment. Doing some global exercise. So we're going to talk from, you know, physical

cognitive standpoint and activity analysis and care partner training. So we will jump right in because I want to make sure that I get all this information to you all. Okay. So we're going to start with home evaluation. So home evaluation is going to probably be one of the first steps in your OT process. This is going to involve an OT coming to your home and just inspecting things that are possible risks. So we're talking about fall risks or you know, just safety hazards or just things that can improve your day-to-day life.

We're looking at things like grab bars here, where to install them the right positioning to install them actually matters. Little things like having a handheld shower can boost someone's independence greatly. Also things like lighting or contrast. So color contrast, if you look at the stairs in this picture, just that difference in the tread and the riser is going to increase our client's visual acuity, which means that there's less of a chance of them tripping and falling. So even little things like that, we might suggest the height of seating. So this one can go both ways. We might suggest a shorter toilet or lower chairs. If you're vertically challenged like myself, it's hard to get off of one of those tall chairs or a tall toilet, my feet dangle, and it's not safe. But then if you're tall, like my Papa, you probably need a taller toilet.

So these are things that we're going to suggest. They're going to make our patient's life easier and your life easier. A few other things, non-slip surfaces, gone are the days of the suction cup shower rugs or whatever. We don't like those, those aren't safe. They actually have like different materials that you can put on your tile that safe, that will make a texture in your shower, having a shower bench, furniture layout. We're talking about things as big as a stairlift so that our loved ones can still get up and sleep in their own beds. This is actually one of the places that I find people are most resistant is if they've lived upstairs their whole life. And that's where their bedroom has been. They don't want to move their bedroom. So something like a stair lift, we might recommend, also like lighting changes or little things like these new wireless doorbells, like the ring doorbells.

So when we hear the doorbell, how do we usually react? It's like, right? Like oh, we got to go get that. Well. That's when we're gonna fall, is when we're in those kind of situations where we're trying to move quickly, we're flustered. So with a doorbell like this, you could look and say, oh, it's just my buddy, the Amazon guy. I don't need to get up and rush, or you could even speak to them through the camera and let them know that, you know, I'm coming to the door, go ahead and let yourself in. So just some different kinds of changes. In this home evaluation section, we're talking about things that are a little bit more heavy lifting. So we're going to make these suggestions. However, we're probably going to refer you to a general contractor or a home modification specialist, something like that, to do the installation, because these do have something to do with the structure of your home.

So that part is not really up our alley. But these things, these adaptive equipment options and some environmental modifications, these are things that we can do. These are kind of the smaller, cheaper, a little bit easier to find type things. So with this adaptive equipment I'll tell you, my favorite thing on this page is the the bed cane. So I actually had a patient who had a Parkinson's diagnosis and she was the first person I saw with one of these. And she was getting sucked into her couch and she had one of those really nice soft couches. And once she sat on it, that was it. She wasn't getting back up unless someone helped her. So she discovered one of these bed canes. It was able to go in her couch and it's super light, easy to move.

So if she was embarrassed, when she had guests come over, she could kind of tuck it in the closet. It also has a little bag for your remotes. It helps, you can use that in your bed and it's let my Papa be able to scoot himself up on his own now. So we don't have to help him, you know, every time he kind of slides down. We're also going to be talking about things like these silicone handles. There are so many different options for like utensils and eating things. I could have done a whole segment probably just on kitchen adaptive equipment, but those things are going to try and we're trying to make these people more independent. At the end of the day, all these things that I'm talking about are mostly treatments for the person who has Parkinson's, but this is affecting the person who is the care partner, because they're not having to provide all this care when said person is more independent in an area.

So silicone handles toilet, riser, shower chairs, things like that. All of these things are to increase safety so that the person needs less assistance. The reason that you want to come to OT instead of just ordering all this stuff off of Amazon yourself is there's training involved, not everything here is used as it appears. There are special ways to use a shower chair that pokes out over the edge of your tub. There are safety steps that we can help you with as well as we might have things in our office already that you can kind of try out before you purchase. And we'll have access to catalogs that have further beyond what Amazon offers. Okay, next, we're going to talk about an activity analysis. This is one of my favorite parts of OT.

When we were in college, this was something that we focused on really heavily, and it was, it's just, I don't know, I think it's probably my type A personality, but I really like breaking things down and finding that one step where something's going wrong. So basically, that's what these activity analyses are. We're going to come in and we're going to say, hey, let's go through a task that you typically could do on your own. And let's see what the holdup is. Where are you getting stuck? So to show you kind of how deep an occupational therapist mind thinks I want you to think to yourselves, I'll give you like 30 or 45 seconds. I want you to think to yourself, how many steps does it take to make a simple glass of chocolate milk? So I'm going to give you a few seconds, but just kind of count counting yourself in your head, see what you can come up with.

Alright, how are we doing? So did anyone get around 25 steps? Probably not, right. That sounds really excessive. Like it's just chocolate milk. Well, we're going to break these things down. I'm going to run through the steps that I came up with for it. Honestly, I probably could have went a little deeper, but for the sake of time, I didn't. So the first step I'm going to think of is, well, I have to get to the kitchen. So I'm either going to have to stand up from a sitting position or from a lying position, right. Then I have to ambulate to the kitchen. Once I'm in the kitchen, I need to be able to open up the cabinet. I need to be able to reach for a glass. I need to be able to grab onto the glass and then lower it without dropping it.

And then let go of it. Walk back over to the refrigerator. Now I'm going to open the refrigerator. I have to reach in, pick up a gallon of milk and maybe my chocolate syrup, turn, walk some more, set these things down. I have to be able to open up a drawer and grasp a hold of a spoon, twist the cap off of the milk, pour it in. However my chocolate syrup or chocolate powder works, whether I have to take the lid off and scoop some or have to squirt it in that's another step. Then I have to be able to get my spoon into the top of the glass, that can be tricky with our tremors, I need to stir until dissolved, I need to be able to carry the glass wherever I'm going. And then I need to be able to drink out of it without dumping it down my shirt.

So it's a lot of steps. And the reason that we don't think about things like picking up a spoon or opening a drawer or taking off a milk cap is because those things are almost like involuntary to us at this point in our lives. Our brain is really, really good at making shortcuts for things that we do a lot. And so then it has this shortcut. And so that you really don't have to think about picking up a spoon or taking the lid off of something. Unfortunately, whenever you have tremors or Parkinson's or several other different diagnoses, those little steps are going to be where you find hang-ups. And that is going to be, why are people quit doing them for themselves? It's well, I can't get the cap off the milk anymore. I keep dropping my spoon. You can ask, those are the reasons that they stopped being functional is because they don't want to be embarrassed by the small steps that they're having trouble with.

So with these activity analyses, what we're going to be doing is we're going to come in and we're going to want to watch them do something that was once an activity that they enjoyed participating in. Maybe it was their responsibility. Maybe your loved one used to be the one who was in charge of feeding the dog every day. And now they get the dog food out of the garage and they're walking through the house with it and they're spilling it everywhere. And it's just easier to do it yourself. Right? OT doesn't like that. We're going to say no, no, no. Let's move the container closer to the dog dish. Let's get a container that has a lid on it so that they can still carry it or better yet. Let's just buy automatic feed, an automatic feeder. So it's nobody's responsibility. Something in the kitchen, if your loved one used to be the cook, and now they're not safe in the kitchen.

Let's figure out why they're not safe in the kitchen. Maybe it's because you don't trust them with a knife, but their tremor, something like this cutting board pictured or a chopper a food processor or something like that. There might even be times where we'll suggest, hey, you know what? Your loved one actually is safe to do all the prep work. Like they're good sitting down chopping. What we're worried about is standing at the stove. So then we'll tell them, hey, why don't you have them do all the prep, work for dinner a couple of days a week. And then you come home and you, you know, you do the cooking or you take over whenever it gets to the point where there's some heat involved.

Okay. So it really is about just adapting and overcoming. That's kind of how OT looks at things. If your loved one used to love gardening, and now they can't get down on their hands and knees and garden anymore. We're going to build raised beds. It's all about relearning ways to do things that you used to be able to do that meant something to you. Now we're going to get into this is the one that nobody really likes to talk about, but it really is important. So exercise, we're going to start out talking about just some physical exercise.

So research shows that a regular physical exercise can improve coordination, strength, balance, gait, tremor, flexibility, strength, and mental health. That's a lot of stuff that you may be able to lower medications for. Right? We are definitely going to encourage physical exercise for anyone that we see. It doesn't matter what the diagnosis is, it's good for everyone. However, for our patients with Parkinson's, there's more to be sought after with this exercise. So I'm not going to go crazy into detail about physical exercise too much just because there are tons and tons and tons of Parkinson's dedicated exercise programs out there. Things on YouTube, physical therapists are really good in this area, and I kind of want to touch more on exercise and the process of exercise improving your mental health and slowing the progression of neurodegeneration. So things like Parkinson's disease, things like dementia, where it is a neurological diagnosis, and it's going to progress, we're aware of this, right?

So as that's happening, what we want to do is we're going to encourage exercise specifically things that involve getting your heart pumping, increasing your oxygen intake. So aerobic or cardio exercise, which don't worry, we're not talking about treadmills. Or at least I'm not talking about treadmills. But so it's been, there's tons of research that is still going on. And lots of it that has already been done to show that physical exercise and increasing the oxygen level helps our body to engage in neuroplasticity. And so what neuroplasticity is, is it is our nervous system's ability to strengthen and continue to use old circuits within our brain, as well as establish new ones. So this is why maybe you've seen someone who has got a stroke, like my Papa that I was talking about earlier, he had a stroke about 16 months ago.

And because he lives with a therapist, he was immediately doing therapy after a stroke and he's regained back all of his function, his leg still gets heavy. It still gets tired. It's not quite as strong

as the other one, but he can still walk independently. And that's because we started those exercises immediately. That's what I suggest to anyone as soon as you find out that you have a Parkinson's diagnosis, get signed up for some kind of program where you're going to be exercising regularly. So if you think about that neuroplasticity, if we're exercising, we're growing those new connections, and we're trying to strengthen the old connections. As the other ones are kind of declining or degenerating, then we're kind of maybe evening it out a little bit, which is how we slow the progression. So it's not necessarily that you're going to improve bounds over what function you're able to do now, but maybe just hold on to what you have currently.

Okay. Another thing, so like I said, no treadmills, you don't even have to lift weights. Any OT will tell you that the best kind of physical exercise is the kind when you're being functional. Again, this is helping my care partners out because now you guys get to give back some responsibility. So like pictured here, one of the best things you could do is have your partner do some laundry. Think about all the movements that are involved in laundry, right? Like reaching and lifting and squatting. And then if my patient has Parkinson's and they're folding, I'm going to encourage them to do these big, exaggerated movements when they're doing those things, because I want them stretching and getting those big movements in that you'll hear suggested in most Parkinson's exercise programs. Even something like, you know, cooking a meal or you know, doing a YouTube exercise class or something like that is an option that we might do.

And then last for this physical exercise is fall recovery. So this is one that maybe we don't necessarily think about too much as an exercise, but unfortunately, people who have Parkinson's fall a lot, it tends to happen to everyone at some point. Falling is bad, it stinks. None of us want to deal with it, but when you fall, can you get back up and can your care partner help you get back up without hurting themselves or also ending up in the same position? So let us come in and teach you some fall recovery. This is an area that PT also can help you with. Just kind of learning those ways to take some of the strain off of you physically. We're gonna move in now to, sorry some cognitive exercises. So something that you know, we typically think of when we think of Parkinson's is a tremor or maybe stooped posture, maybe shuffling, right?

Those are the typical things that come up. Unfortunately there is more 50% or more of people with a Parkinson's diagnosis are eventually going to be diagnosed with mild cognitive impairment or possibly dementia. What mild cognitive impairment means is it's kind of like thinking about your brain shifting down a gear. So it's not one area of the brain necessarily that you're having trouble with. It's kind of global, but it's just like, everything's kind of slowed down a little. So in our clinic we see, everybody we see has something like this. Everyone we see has some kind of cognitive decline of one type or another, and they're pretty surprised to learn that just like your body, you can exercise your brain too, and your brain can improve. Again, that neuroplasticity, right? So if I want to get big biceps I'm not going to go to the gym and walk on a treadmill every day, right?

I'm going to lift some weights on the same thing. If I want to improve my cognitive function, my attention, my memory, my processing speed, my speech, problem-solving and all those kinds of things. You know, I'm probably not just going to play solitaire. I need to do something that's challenging my brain, challenging those other parts. So one of my favorite activities as an OT to do is cook a meal, follow ingredients, follow a recipe. Let's see how we do, we'll start simple. And if you do really good with a simple recipe, move on up to something more complex. You want to be at any kind of exercise. You want to be at a level where you are challenged, but it's not impossible, right? Because if there's no challenge, then you're not really benefiting from it. In our clinic, we do things a lot of like pencil, paper tasks.

We do things on computers. We a lot of different activities, Sudoku, and you know, different puzzle things. Behind me, we have a driving simulator that we have some of our patients use, kind of just a very big realm of things, but always, always, always the best treatments are functional ones. We are right next to a grocery store. So we'll take our patients grocery shopping, practice with a cart. Can you find the aisle that has the crackers? Can you get through the store as efficiently as possible with our grocery list, paying bills, things like that, paying, you know, paying a bill over the phone with a credit card can be pretty challenging sometimes. So maybe I'm going to have, you know, maybe I'm going to have your loved one do that instead of doing paper pencil tasks today, so that I'm challenging those parts and I'm still keeping them, keeping them active and last for our ergonomics in body mechanics.

So this is where we're kind of looking more at the care partners. So the chances are that if you have a loved one with Parkinson's, there's definitely at some point you're going to have to get them out of the car, right? Get them out of bed, get them off of the toilet, something like that. In that process, there's a right way and a wrong way. Whenever I was a nursing assistant, I remember getting really envious that my patients, when they were with their therapist, they only needed one person to get up and like a gait belt. But whenever I was trying to get them out of bed, we had two people and a Walker and a gait belt and, you know, somebody holding the wheelchair and it was always so complicated. And whenever I went to school, that was one of the first things I wanted to learn was like, how do you transfer people without it being some like big situation?

And there are tricks. I'm actually gonna show you. But using things like gait belts so that you are safe, wearing safe footwear, having a clean environment, no clutter taking away those tripping hazards and things like that. And then learning proper lifting techniques and transfers. All of these things are really going to be helpful. You know, if you think about just the fact that what happens, if you get injured, who takes care of them? You know, we were talking, they were talking earlier about, you know, going into a home or something. That's a long process trying to find some respite care. So if you get injured and you have to find respite care quickly, then it's

gonna be a difficult situation. So we want to help you avoid that. So we're going to get up and move around a little bit.

First of all, if you are at home and you are a fall risk, if you have any chance that you could be injured or hurt yourself during this, please don't do it. Make sure you have someone next to you or do them seated. I'll try and show you some of them seated. But the first thing I want to talk about is posture. We all have posture problems. I was just looking at pillows this morning for my neck pain. So I want to show you some stretches. These are some things that you could do with your care partner and your loved one, maybe every morning or at lunchtime or something. It should take about three minutes. Each one is about 30 seconds long. So one of the things that is a concern for us when we are talking about people with Parkinson's again, that stooped posture, right?

So we see a lot of this, all right. Our body's natural reaction is to start going inward. So when we get into that state of flexion, think about walking, where is it? Where am I looking at? I'm looking at my feet, which that's a no-no, when we walk, we don't look at our feet. We look at our environment around us. So we want to bring that posture back to here. Okay. We want to have our head up and be looking forward. So the first one I'm going to show you is pretty simple. Anybody can do this with, using a wall and again, if you need to stay seated for this, you can do this in a chair. Maybe not quite as effective, but still works. So you're going to stand up against a wall. And the goal is to have your heels, your butt, your shoulder blades, and your head, all touching at the same time and you'll kind of do that wing shape with your shoulder blades, where you're feel like you're trying to pinch something back there. And what this is going to do is it's going to open up your chest and stretch these neck muscles. Now, if you're not already in that stooped posture, this might not seem that difficult. However, you can ask the people that are like this, that's not an easy thing to do. Okay. So now we're going to go through the six stretches for just your neck. I'm actually going to sit down and do these ones.

Okay. So the first one that we're going to do is we are just going to look side to side, and we want good posture through this whole thing. So keep your shoulders square and you're looking forward. And for all of these neck exercises, we're going to hold onto our chest right here, because our bodies have a tendency to kind of cheat a little bit. And if your chest is stretching, then your neck muscles aren't going to be as much. Okay. So we're holding on and we're just going to go side to side. And where you should feel this stretch is right here. So you have this muscle, it's your sternocleidomastoid, I'm sure I butchered that, it is connected to your sternum, your clavicle, and your mastoid process back behind your jaw. When we get this posture, what actually happens is those muscles get trunk up. This is kind of gross, but I think about like like beef jerky, it goes from being like this big to this big, it shrinks. So as you can imagine, you're being held like this. So that's that muscle right here.

Okay. The next one that we're going to do is up and down. So we're just going to look up and look down as far as you can go, holding down those chest muscles. Again, I'm feeling a lot of stretch here. Not as much in the back of my neck, but a lot in the front. Okay. The third one, you're gonna look a little funny doing these. So the third one, I call it the chicken. So you're going to go forward and back. So this angle you go out and back. You're going to have a few chins when you do this one.

Good. Okay. This one's the hardest one. The video I originally watched, they called it the Janet Jackson. I don't have much rhythm. So you hold onto your chest and you're going to try and just move your head. Okay. This one is actually targeting these muscles that are in the back that connect to the base of your skull. So it's kind of a weird feeling. You actually feel it like on the inside of your scapulars. Okay. This one's my favorite. I really feel this one. So hold onto your chest. And you're gonna put your head to the side, when you're doing this, you're not thinking about bringing your ear to your shoulder, you're thinking about bringing this ear as high as you can. So we're trying to bring it as far up to the ceiling as we can. And then switch. Again, this one, you should feel the side of the neck and you even feel at some in your traps.

Okay. And the last one, again, holding on, we're just going to do a half circle, so you're going to go forwards. Okay. All right. Good. So again, three minutes a day, and that could really increase your loved one's visual acuity, could help your neck pain. Good for everyone. Okay. So I want to show you guys a trick. So those transfers, one of my favorite exercises to have my patients do, who have pretty much any kind of physical diagnosis related to aging at all, is sit to stand practice. So whenever I'm trying to get up from a chair, if I'm leaning back and I have my legs, see if I can kind of tilt this down so you can see my feet.

If I have my feet kind of spread out in front of me, I'm leaning back. I have all the things working against me. Gravity's not going to help me here. I'm not helping my care partner. If they try to pull me from this position, they're gonna hurt themselves. So a few simple steps. First thing is you say, scoot forward, you're gonna come up to the edge of the chair, not to the point where it's tipping, but to the point where you're just barely on it, you're going to bring your feet back. You want your feet behind your knees. So when I look down, I shouldn't be able to see my toes. I should only see my knees and carpet. Now, if you had a Walker, you had a grab bar or something like that, you would hold on somewhere differently, but we're going to hold on right here.

So we're going to push ourselves up. Now, this is the trick. When you are going to stand up, the only thing you need to do from this position is lean forward. Don't believe me, try. So from here, we're just going to lean forward, put the weight on your toes. Once you get to a certain spot, you'll feel kind of gravity shift you. And then it's really easy to just pop up because all you have to do is use your knees, all you have to do straighten them. So you're going to push

yourself forward, nose over toes. And as you get to the point where you can feel gravity shift to your toes, then you're going to straighten your knees. And this works really well whenever you have a gait belt on someone. So you want to put the gait belt right around here, where their center of gravity is at.

Okay. If I'm leaning forward, I'm putting my center of gravity forward and it's pulling my bottom up off of that chair. Okay. So we're using that gravity to our advantage. Okay. And then for cognitive exercises since we're on here I didn't have anything interactive because I can't see you or hear you. So just to give you a few ideas one of my favorite cognitive exercises to do with pretty much everyone is verbal fluency. So I'll just say, name as many breeds of dogs as you can, as many as you can, or maybe I'll say, tell me as many words as you can think of that start with the letter M in one minute, no proper nouns. So no like names or cities. So if I do that and they are spitting them out that same center of my brain processes information when it comes in.

So I'm increasing my processing speed by just saying a bunch of words, really fast. The goal that you want to hit is about 11 words per minute or more. Also I like to do this working at a working memory activity where we'll say, I'm going on a camping trip and I'm bringing a tent. And then my patient will say, I'm going on a camping trip and I'm bringing a tent and a flashlight. Then I'm going to go attend a flashlight and a sleeping bag. And we're going to just keep going back and forth and see how far we can get. Sometimes it's kind of embarrassing cause sometimes my patients can remember better than I can. I try to sneak and take notes in session, but another one is simple item retrieval activities. So say, hey, can you go get me the flour, the cinnamon, and the butter, but I want you to wait three minutes and then go get it. So what you're doing there is you're changing from working memory to short-term memory. So working memory, I just have to hold onto it just for a few seconds. My short-term memory, I'm going to have to grasp it a little longer and then any kind of puzzles or anything like that are going to be good for you. Okay. I'm going to go back to sharing my screen now.

Let's see. There we go. Okay. So moving on, our last topic here is care partner training specifically. So again, I know a lot of this seems like it's geared more towards your loved ones. But our whole goal is making them more independent so that you don't have to do as much for them. So these are my burnout tips. First of all, burnout is a real thing. It happens. I've seen it time and time again, if you don't experience caregiver burnout at some point, then you are some kind of saint. First thing is get help where you can. Take it. When people offer to come and sit with your mom or your husband or whoever, take the help say, sure. Yeah. What day would be good for you to come over for a couple hours or yeah, you can take them to lunch, let other people share some of that responsibility.

And with OT, we can brainstorm. If you don't have family or friends close, you're by yourself somewhere, you know, we'll come and help you, we'll try and help you figure out some exercise

programs or some support groups where they could go without you there. The next one is scheduling time away. So it's important to take breaks from each other. My husband's grandparents have lived with us for 16 months and we were really open with each other about not wanting to, you know, smother each other. And so we take weekend trips a lot. We'll go stay at an Airbnb just like in the next town over even just to have a night away. And then have, you know, his mom, my husband's mom will come and stay with them, or they will have a day where they're set up where I just know that they're going to be safe because our neighbors are home.

So it really is important, you know, weekend trips, that kind of thing. You need to fuel yourself if you don't want to run out of gas. So it is very important for your mental health to keep feeding yourself, you need to fill yourself up. Okay. And then also scheduling time with each other. There are so many parts of caregiving that are un-fun, right? There are a lot of stuff that's not so fun, but don't let that un-fun stuff get in the way of still having some real interactions and some real moments with your loved ones, play board games, watch football together. You know, have a movie night. We do that a lot in my house. We'll find a movie that we think everybody's gonna enjoy and will suggest, hey, let's all just pile on the couch tonight and watch this together.

Have a meal together once a week and just talk about anything other than Parkinson's. Keeping your loved ones as independent as possible. So again, this is OT, this is all that we care about. At some moment in every every client that I see, there's some moment where I tell them my job is simply to make you as independent as possible in whatever it is that you want to do. So if they want to cook again, if they want to help out around the house, again, silly things like tying their shoe or putting a sock on for them will turn into something that you're going to have to do forever. So let's not do it, have an OT come in and teach them how to put their socks on a different way, find a different way to tie your shoes or buy different shoes that you don't have to tie. We want these people to be independent because again, if they have purpose, they're going to feel more fulfilled and you are going to be able to get a little bit more of a break.

So getting organized, this part I'm super type A, so I have a hard time sometimes remembering, like not everyone uses nine or 10 calendars to get through their life. Using things like calendars, having routines, having an alarm set on your phone for things, or for them, keeping alarms set so that they remember to go take meds, while they can take them without help. Having especially the solid morning and evening routines are really helpful because it's just kind of those end caps of the day where like, you know what I know what's going to happen at those times. In the mornings this is our routine every single day. This is just how it goes. I know that it's going to take two hours for them to go from getting ready to, you know, getting out of bed to being ready to go to the doctor's appointment.

And in the evenings, I know that for them to get in bed by 10, they have to start getting themselves ready at 8:30. You know, prepare for that kind of thing. You want to link new things to old routines. So if there's something new that you're trying to, you know, put into your routines, try putting it with something that you don't forget. So for me, it's coffee, like if I have to take a new medicine or do something that I don't typically do in the mornings, I'll just put it with my Keurig because no way that I'm going to forget to drink my coffee. And then planning accordingly. So this is both, you know, like medication-wise, so somebody had mentioned that earlier about being a facility and how important it is. It really is important that medications are scheduled correctly with Parkinson's.

I've had patients where I've went in to get them to exercise for the day and they haven't had their carbidopa yet and or levodopa and they are just stiff, right? It's just not going to happen. And then an hour later I come back after they had their medicine, they're a whole different person, super important. And then also engaging these people in activities outside of you. So things like I know a lot of the YMCAs have Parkinson's exercise groups, having them go to like a delay the disease class or a Parkinson's boxing class a couple of times a week, not only for the benefit of exercise, but the socialization right. With Parkinson's, depression is very common. With isolation, depression is very common. So let's try to balance that out where we can, keep them as social as possible, keep them engaged. And then while you have them at those activities, you can go and you can, you know, get your nails done or get your errands ran.

Okay. And so I saved the best for last here. So self-care, thankfully we do live in a much kinder world in terms of this now. So people are starting to kind of recognize more and more that it's important to take care of yourself. And I always think about on an airplane when they tell you like, you know for your oxygen mask, you have to put your own on before you can take care of somebody else. That applies everywhere. I cannot care for my loved one effectively if I, myself am running ragged. So doing things like journaling, I put my headphones in a lot when I put my headphones in, people tend not to talk to me. So I'll stick my headphones in whenever I cook dinner, that gives me like a half an hour where it's just me and my podcast or my music.

And it's enough to kind of give you that little bit of a reboost. Also, you know, making memories together. So continuing to find ways to enjoy each other. I'm very aware of how difficult it is to travel with someone who has a neurodegenerative diagnosis, but it's still worth it. It's still worth it to take that stuff and do it and let OT help you. We are really, really good at thinking 10 or 12 steps ahead and saying, hey, you know what, if you want to go on a road trip, you totally can, but let's set it up this way so that you have, you know, you're taking extra time to get there, or you are planning out bathroom breaks at cool spots along the way. Okay. And then my final tip here, not so much an OT tip, as just a human tip.

I have had the privilege taking care of a lot of people at the end of their life. My family included, and I can promise you that none, not even one of them is still upset about the time that Thanksgiving dinner was two hours late. Nobody cares about the time that dad helped wrap the Christmas gifts and they look like a dumpster fire under the tree. Nobody cares. That's not the stuff that people are going to hold on to. Take two extra hours to make Thanksgiving dinner so you can spend it together, let them wrap Christmas presents or birthday presents, let them have fun and be a part of things still. Don't take life so seriously, try to find fun where you can. And then if I still have time and they did ask us to give you guys a few action steps. Is that okay?

Polly Dawkins:

Absolutely.

Amber Crawford:

Okay. So a couple things real quick. So lids, if you have somebody with Parkinson's put lids on stuff, everything, so they can still carry it around or buy deeper containers for things, play games together. So not just for fun, but for that cognitive stimulation. So we want things that are a little bit challenging, anything that involves strategy. So like playing different card games is really good. Pictionary, Yahtzee, anything like that, where there's a little bit of thought involved. It's going to be great. And then allowing extra time for tasks. So like my Papa really enjoys grocery shopping. And you know, at 86, he's not that fast anymore. And it's definitely not easier for me to shop with him, but it's meaningful to him. He likes to go, it makes him feel like he had a purpose for the day.

So once a month or so we go grocery shopping together and it, he looks at all the lunch meat and usually takes several hours of our day up but when we go home that day he's fulfilled and he's happy and he has something to talk about. It makes all the difference. And at the grocery store, the carts are really good for providing some balance. I like walking with carts there. It's pretty nice for our people with balance issues. Okay. And then I have two Parkinson's specific things that I wanted to talk to you about. So first one is if you have your partner doing exercises. Again, posture is a problem with our people with Parkinson's. And I will tell you one thing about being a care partner that gets old is repeating yourself. So have them in front of a mirror, have a mirror and tell them you are responsible for checking your posture.

You might have to give them some cues, but now, instead of saying, put your shoulders back, bring your head back, you know, the whole thing. Now you can just say, hey, look in the mirror, do you look like you're sitting up straight and they can kind of self-correct and then last do we all know what freezing is? So it's probably one of the most frustrating parts of Parkinson's. Freezing happens a lot like in a doorway or a threshold of a room. And when this happens, our body just kind of decides to rebel and our brain is saying, hey, let's walk. And our body says, eh,



I think I'm just gonna stay here. So when that happens, a good trick for you to do is to tell your person, so typically it'll happen something like this, where they're like mid step and they just get stuck. And so what your job is, is to say, hey, take a step backwards and tell me, what is your mom's middle name? And then go again. So what you're doing is that is a little bit of an interruption between your brain communicating with your body, just hitting the reset button. You're telling your brain stop thinking about that. And then when you come back, it's like you hit the refresh button. I think that that's all that I have for you.

Polly Dawkins:

Thank you for being here today.

Amber Crawford:

Thank you. Thank you so much.

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