



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

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Davis Phinney Foundation

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

Amanda Craig is a licensed occupational therapist and owner of ADA Therapy Services in Boise, Idaho. She provides individualized outpatient treatment for adults and adolescents who experience real-life deficits caused by neurological and chronic conditions. Amanda and her husband have five-year-old identical twins and enjoy mountain biking, skiing, and cooking. Are we going to get to see them run around in the background?

Amanda Craig (OTR/L):

Luckily, my husband took them away from the house today, so I can have some peace and quiet..

Melani Dizon:

All right, good. Real quick, yes, you're going to get copies of all the slides and all of these presentations. So Amanda, all right, take it away.

Amanda Craig:

All right. Thank you. Let me share my screen with you guys here. Okay. Can you see that? Okay. Yes, we're all good. All right, good. So thank you for having me today. As Mel said, I'm Amanda Craig. I'm an occupational therapist here at Boise, Idaho, and the owner of ADA Therapy Services. I'm excited to be here. I'm a little nervous. So I have my notes here in front of me to keep me on track.

Prior to starting my private practice here in Boise, I worked for one of the larger outpatient hospital clinics here as part of the neurological and brain injury team. And I decided to break off on my own into private practice to focus on some of the diagnoses and clients that I'm passionate about. And that includes Parkinson's.

So I have to tell you that Parkinson's is one of my areas of passion and treatment because some of my all-time favorite clients have been those with Parkinson's. They have been some of the smartest, funniest, most well cultured, hardworking, and open-minded people I've ever been fortunate enough to work with. On a personal note, I'm from Carlisle, Pennsylvania. I'm married to a Boise native. So I've been here for about 15 years, and we do have five-year-old identical twins who are a lot of fun.

So I wanted to start by telling you what occupational therapy actually means. So in the world of OT or occupational therapy, the word occupation does not actually mean vocation. So let me get that out of the way in the beginning. What occupation actually means is any activity in that

occupies—that's the key word—that occupies your time, your physical, your mental, and your emotional energy. So wait, you say. That could be anything that occupies all of my life and yes, you would be right. So occupational therapy can actually address any activity that you need or want to do in your life. Occupational therapists subscribe to the idea that humans need to be occupied to be satisfied. So that includes your ability to be able to care for yourself, like dressing, bathing, and grooming, to care for your house, like cleaning, shopping, and taking care of your loved ones, like your kids, your spouse, your pets, and getting around the community such as driving or using public transportation.

So occupational therapy works in all of these areas to help you be as independent as possible for as long as possible. So with that in mind, today I wanted to talk to you about a few ideas that I have for you to help you live well at home. A lot of us are obviously spending more time at home these days due to the current pandemic, but even prior to COVID-19, I had a firm belief that home is where the magic happens. Most of what we do happens at home, and therefore home needs to be a safe and comfortable place for ourselves, our family, and our guests. Most of us obviously eat, sleep while being at home, but we also cultivate our passions at home. We exercise at home. We create art, food, and music at home. We study and educate ourselves at home, and of course we visit and maintain relationships at home. So home needs to be a place that supports those goals and allows us to thrive in our natural environment.

So when I'm considering home modifications for anyone with a diagnosis like Parkinson's, I try to look at the cognitive challenges as much as the physical ones. Some of the challenges present for people with Parkinson's include those here on this slide. And that may be things like processing speed delay—so how quickly you are able to see, hear, think about, and react to something? Multitasking challenges—so that's doing and thinking about more than one thing at a time. Planning deficits and making decisions, and people with Parkinson's may have decreased internal cues. So that's that little voice in our head that tells us what we should or shouldn't be doing next. So these among other challenges can all contribute to further problems in safety and efficiency.

So with that, many of the symptoms with Parkinson's can cause safety concerns at home. And we also have to consider any medications that may contribute to safety issues. Things like fatigue, blurry, vision weakness, medication side effects. But we also think about what diagnoses the other person may have in addition to their Parkinson's diagnosis. So that could be diabetes or sleep apnea, depression, anxiety, vision issues, hearing impairment, heart conditions, blood pressure issues, both high and low, obesity, dementia, foot issues, skin integrity problems, wounds, and current or past alcohol use or drug use. And in addition, a general sedentary lifestyle.

So for all of these potential reasons I just listed, these can all cause safety problems at home that can increase the number of falls in the home. As Hannah was talking about, it can increase just a fear of falling. Even if you haven't had falls, it can create an impaired sense of smell or hearing. So you may not notice when emergencies are happening as they're happening. And if someone does

notice an emergency happening, they may not have the processing speed skills or the reaction speed skills to react quickly enough to the emergency. So these can be at all an increased risk. And so we really want to make sure that the home is as safe as possible for those with Parkinson's and their care partners.

So if you or your family are experiencing any of the challenges or safety concerns that I mentioned, I want to share some ideas with you that you could try out at home. First, you may want to schedule an appointment with an occupational therapist or a physical therapist to do a home evaluation in your natural environment. That might be something that you want to put off on hold until after the pandemic and to invite somebody into your home, but just keep it in mind. And when I say home, I do mean that's anywhere that you might be living. So that could be a house, an apartment, a trailer, the place that you live with your adult children. It could be an independent or assisted living facility or a memory care facility. All of these are appropriate places to have a therapist come in and make sure it's a safe place for you.

Homes therapists come in all different shapes and sizes. So not all OTs and PTs perform home evaluations. So you'd want to find one that does just by calling your clinic in bigger cities. You can also find people who are certified in home evaluations and home modifications through some of the credentialing organizations, but I won't go into that bit of information here. The OT or PT that you have do a home evaluation may also may not be a home health therapist. So don't let that limit you. If you're not currently receiving home health therapy, outpatient therapists like myself can actually do home evaluations under the Medicare insurance umbrella.

So the home evaluation should include some of the aspects I've listed here on this slide. The therapist would come in and take measurements. Maybe they'd take photos or videos of your home. They'd ask you to perform some of your daily, normal tasks in your home, like getting around in your bathroom and preparing food in your kitchen, getting in and out of your closet, maybe feeding your pet.

They might narrow down their tasks that they ask you to do based on what you report is a specific problem. The therapists would also provide you with some recommendations and potential resources. And these might be specific to your needs, or they might be general accessibility recommendations. The therapist should also give you some education on what home changes are dire to make now and what can be done in the future. And maybe a little bit later on, so they can provide you with some considerations, what home modifications might be necessary with the diagnosis progression, which is an important aspect of a Parkinson's home evaluation.

Like I said, looking at things now that are necessary to change and maybe about things later on that could be changed. The therapist can also help you or your care partner consider future options to keep everyone home in the home as safe as possible with as little injury as possible.

And just as a side note, the therapist that performs a home evaluation is usually not the person that will perform home modifications or install items for you, unless you found yourself in unicorn, which there are some out there, but usually it's a separate person.

So one of the key ideas to keep in mind when modifying anything in your home is that you need to find a balance between improving accessibility in the home without reducing activity. For example, people may want our power lift recliner chair like in the picture here to help them get up from seated into standing. And this may be appropriate for a lot of people. But if getting up and down from the chair is the, you know, it might be some of the best exercise that a person receives in the day. And if that's the case, we don't want to take away that exercise and that function by adding a power lift chair that would actually lead the person to decline faster. So when we're looking at home modifications, we wouldn't want to decondition someone by making life easier if the person is capable of more. However, if the person getting up and down from the chair is falling regularly or requiring a lot of assistance that may require another person to help, then maybe that power lift chair is appropriate.

So I just want you to have an idea that the decision requires a complete picture when making home modifications. We want to take all aspects into consideration, and that's not only the person with the diagnosis, but also the family and other people in the home, any medical care that the person's receiving, any pets in the home, general environment, any fall risk for anyone involved, the cost, the time, and whether or not the challenges that we're seeing in the home could be improved with exercise or something else other than home modifications.

So ultimately we want home solutions that will increase a person's engagement in an activity. We want any modifications in the home to allow the person to increase their overall participation. And we also want to contribute to maintaining or improving overall health and wellness. So it's a big picture that we're looking at when talking about home modifications,

Okay. Ideas that hopefully you could use in your own home. I don't have time today to go into higher level of modifications like ramps or wheeling showers or walk in shower stalls, kitchen modifications, toilet variations, and other big ticket items. So I wanted to focus on some of the simpler changes that you could start today.

A lot of people are worried that changes to their home to accommodate someone with challenges creates a stigma of impairment aesthetically in the house, or they worry that the modifications will affect the resale value of the house. Luckily though, for most of us, comfort, ease of use, and general accessibility is actually in and desired by most people. So I want you to consider that most people actually want lighting that is adjustable and helps with visibility in all tasks in their house. Most people want motion sensor lighting inside or outside their house or in the garages.

Most people want walk in and no barrier shower stalls. Most people want comfort-height toilets,

and most people want easy access and entryways on doors without having to haul groceries up a bunch of stairs. So for an example, and this is a bigger ticket item, but like in the picture here, this entry way is called a zero-grade entryway. It goes right up into the door with no steps or anything like that, but this is actually a really desirable entryway for all ages and lifestyles. So a lot of changes that you could make to help you live in your house better may be desired in the general housing market.

The home modification ideas I'm going to share with you today can also be implemented at any stage in the Parkinson's process. So these are changes that you could put into place if you've been recently diagnosed with Parkinson's or beyond.

I've also provided a simple checklist I think that you may have received. It's a guide and checklist to go through in your house and look at some of the things that may be safety concerns in your home. And you can go through and think like a therapist when you're answering some of these yes-or-no questions on my checklist.

So for example, if you say no, that, you know, you're having issues with accessing all items in your kitchen that you need to, you know, you want to take that even further and go, well, why is that the case? So is it because of mobility issues? Is it because of strength? Is it because when the items are placed in the kitchen or the layout of the kitchen? So you can start to think like a therapist with that checklist.

Of course, there's many other potential safety hazards that I didn't include on that handout. And the best case scenario would be to have a therapist look over your home and do an evaluation, but hopefully the checklist helps you to start thinking in that direction, and it might trigger some areas that need your attention.

And just note, before you make any changes to your home, if you rent, make sure you check with your homeowner or property manager before you start doing things and installing things.

Okay. So first I'm going to talk about lighting. Lighting is really important. So I'm going to spend some time on lighting here today. Lighting can make all the difference, especially when someone has a neurological diagnosis like Parkinson's. Lighting needs are different depending on the person, the room, the activities in that room. And so I want you to consider that poor lighting can create glare. It can cause cast shadows in the home or on the activity you're doing. And that glare cast shadows can make it hard to do things like get dressed. It's hard to find the opening and your sleeves and your shirt to be able to put it on if your lighting is poor in your closet, bathroom, or your bedroom.

Additionally, cast shadows and glares can also make people think that they're seeing something that isn't there. This can actually increase hallucinations and delusions if a person is already prone

to them with a diagnosis such as Parkinson's or Lewy body or some other diagnosis.

So harsh, harsh lighting can also require a person to have to visually adapt. Your eyes have to get used to going from light to dark and dark to light when you switch rooms. And that can be hard on you visually and neurologically.

When setting lights for a home, you want to consider who's using it the most and trying to be at that person's height, where they spend their time. So if you or your spouse are in a wheelchair, you want to bring that to the attention of whoever's modifying your lighting. That perspective or vantage point can make a big difference. So one example is that lighting that's underneath cabinets like in this picture here can be great for someone with standing, but it can actually create a glare for someone who's seated down lower in a wheelchair.

Lighting can also be really helpful when it's down low, and lighting a walkway or an entryway like in these pictures. Walkway lighting helps with safety and navigation for anyone in the home. This is often done with ground track lighting along hallways, doorways, or pathways, and LED lighting is great for this because it can be placed flat or flush against the wall or the floor. And LED also lasts a long time. So on the left, there's a picture of hallway lighting on the floor, and on the right there's some lighting on the stairs. These can also be set up with some motion sensors. So the lights turn on when you come into that area.

We'll consider providing increased task lighting based on what you're doing. So task lighting is a brighter light directed toward your specific activity, like reading or meal prep or laundry—wherever, whatever room you're doing. And direct overhead lighting can cause some of those shadows or glare, like I mentioned before; they can cast a shadow onto the work surface if you have lighting directly overhead. So you also want to avoid bright, overhead lighting, especially where you're using a screen like a computer TV or iPad. So again, you want to have that side task lighting. One easy method is to add lighting from at least one angle where the task is performed. So like in the picture here, adding a table lamp, a floor lamp, or a wall lamp. From this slide where the person will be reading like the picture on the left is great. Adding two lights from different sides is even better when possible.

Overhead lights do have their place and they're good and they're effective when using the kitchen, the laundry room, with a garage, but more lights is better than one or two big overhead lights. So like in the picture on the right, most houses are doing some of these multiple lights that are overhead, and this is a better solution because it's less likely to create a shadow or glare with whatever tasks that you're doing.

Additionally the location of light matters too, as I said in overhead versus side tasks, but for reading, a task lamp actually be over the shoulder of the person's dominant eye during reading. Unfortunately I don't have time to go into how to figure out which is your dominant eye, but if you

Google it there are ways to tell easily from home. So for example, if a person is right eye dominant, the floor task light would be on the right behind the person's right shoulder. So pointed onto their reading material. However, for writing a tabletop, task light should be on the person's non-dominant hand. So like the picture here, and if a person is right-handed, the light would be on the left side of the desk, angled down to where they write, like in the picture, but she would preferably turn the light on.

I did want to give you a little bit of lighting level ideas just so you could go back in and review this slide later on. A minimum level for a healthy 55-year-old adult adults should be 540 lux. So that lighting measurement unit is lux. I have some other minimum lighting recommendations based on tasks here on the screen. If you're curious how many lux lighting units your home has, you can actually download a free app. Just look up a lux meter app on your smartphone and walk around your house, and it will tell you what your lighting levels are. You will be surprised how low lighting, how much little lighting there is in your house. And also look at it at daylight versus nighttime in the evening.

And these are the recommendations, what your lighting should be in those areas. So you can also consider changing your bulbs out to LEDs. They're more efficient than the incandescent ones like we're used to. And the benefit of LEDs is that they last longer, so they don't require you to change them as often. And there's a picture here of an LED bulb. And then the ones that we're used to on the right, which are the incandescent bulbs.

In addition, related to lighting is nightlights. So I'm sure many of you have heard that you, you know, it's great to have a nightlight to guide your way to the bathroom at night, but we often recommend a nightlight also to be placed in the bedroom if it doesn't bother you or your partner. A nightlight in the bathroom near the toilet or the sink, in any hallways where you might go at night, in the kitchen on one of the counters where you go at night, and even near where the door where you might let your pet out at night, if your pet shares your frequent urination issues.

So the other thing to consider with the nightlight is that a red glow bulb is most often better instead of anything with a blue light emitting bulb. So red glow has been shown to not impact your circadian rhythms as much. And so when you wake up in the middle of the night to go into the bathroom and get a drink or whatever, let the pet out, a red light won't wake you up as much as other colored lights. So you could go back to sleep more easily. A red glow is also more tolerable to many people. So having one in the bedroom might not impact sleep as much. We use red glow bulbs in our house, including our kids' room.

I also recommend that any nightlights you have are the kind of just shut off automatically during daylight so they don't stay on all day. And so I mentioned bathroom earlier, and I learned about this trick from one of my Parkinson's clients. Many people with Parkinson's have frequent urination issues, especially at night. And she uses one of these toilet bowl motion sensor lights on the right

hand picture here that some of you may have received even as a gag gift, but they're actually awesome. So they hang outside your toilet bowl. It senses when it's dark. And when you come into the room, it turns on and it makes a nice, soft little glowing party inside your toilet bowl. It helps you to be able to see to go to the bathroom, but it doesn't disrupt your sleep cycle. You can get them in red or a variety of colors. I know the red ones make your toilet look a little possessed, but you can ignore that part. They're fun for the whole family. And we actually have one of these at our house too. In addition to lighting contrast can be a great way to increase safety in and outside the house.

Contrast means making one surface stand out visually from another. So contrast can be created simply with paint or lighting, floor mats, or whole colors or colored bars. You can also use colored duct tape in a pinch. So aesthetically, many people want accessibility items to blend in. Like they want to grab more to blend in with the wall behind it, but safety speaking, we don't want that. We want the grab bars, the railings, the stairs to stand out for anyone who's using them.

So here's some examples. On the left is painted stairs inside the home, and on the right is a painted entryway. And looking at those, you wouldn't even know that that's an accessibility thing on a house, but it is. It creates a contrast between where each stairs starts and stops. There's also a picture of the powder-coated grab bar that stands out visually from the wall, and they come in all colors and I think they look pretty cool.

Unrelated to grab bars, just some safety notes here—do not install grab bars yourself. Unless you know what you're doing, hiring out to make sure that it's secure and load bearing to a wall. Don't use a shower curtain, a soap dish, a toilet paper dispenser, a towel rack, or anything other than a grab bar as a ground bar. Do not use suction-cup grab bars. If you read the fine print on those, they actually say they're not weight bearing, which defeats the purpose.

A grab bar location is not a one-size-fits-all approach. There are general ADA recommendations for grab bar placement in public restrooms and buildings, but your home, your bar placement should be suited for you, your body, and your needs. And sometimes a vertical grab bar, like the one on the picture on the left, is a better a better use than horizontal grab bar. The picture on the right shows a grab bar rail. That's nice when the toilet's freestanding in the bathroom, when there isn't a place to mount a grab bar near it.

So for technology, I know it can sound overwhelming to learn something new, but there are a lot of useful tech pieces out there for people with Parkinson's to help them improve function. A lot of people with Parkinson's have trouble getting up and down from a seated position to get to the door fast enough when the doorbell rings. And if someone with Parkinson's is rushing to get to the door, this can create a significant safety risk. And so a doorbell camera like this one here can really help with this. You can actually look and see who's at your door from your smartphone before getting up from your chair. You can talk to people at your doorbell through your phone without getting up.

You can see who's at your door from your phone. When you're not home, you can track who's coming and going from your house, like medical staff at home care aides. Also record video to make sure that packages aren't stolen. These typically range in cost for about a hundred dollars, and they do require wifi internet use at your house.

In addition to those, another great tech piece is hands-free devices like the Amazon Echo or a Google Home and other device brands. These are excellent for people with Parkinson's.

Another really cool home modification that I'm excited about are these push-pull rotate door knobs and handles. These can be put on interior and exterior doors. They look like regular door knobs and handles; they're marketed to everybody. But they work particularly well for people with physical challenges. So you don't actually have to grab and twist the knob like a regular door handle or a door knob. You can actually just push it with any body part, like in these pictures, to open the door. And it makes them great for people with tremors. Just a safety caution, note that it does make getting in and out of the house easier. So if you have someone in your family who has wandering dementia tendencies or small children, you may not want to use something like this that makes it easier to get in and out of the house. The ones in both of these pictures are from the brand called Brinks and they're the push-pull rotate model. And they're found at Home Depot.

A challenge for some people with Parkinson's is also turning lights on and off. It can be frustrating and challenging with these regular small toggle switches on the left. I recommend having someone switch out your light switches to low because it's a low cost change, but switching to a rocker switch is much nicer, especially for tremors.

Touch-on lights are the lights that used to be like we ones from decades ago. So a lot of brands have made lights that you can tap the base and turn them on or off, and you don't have to mess with the little knob up inside the lamp. And so you want to make sure that whatever touch lamp that you choose is one that's sturdy and not knocked off easily.

And with a tremor, in addition to touch on lamps, there's kitchen and bathroom faucets that turn on with a tap. They're widely available and great for anyone with Parkinson's. It's also great for anyone with food or paint on their hands. Additionally, changing your handles out in your kitchen and bathroom cabinets can also be an inexpensive fix. So many people like a seamless look in the kitchen without any handles or knobs, but for people with Parkinson's, handles can really improve quality of life. And like the picture on the right, handles that are the longer ones are easier to grip. And then the small round knob one, so a longer handle's better for someone with Parkinson's.

A common problem for people with Parkinson's is that they may have problems pulling out their dining room or countertop chair to sit down. A simple cheap solution is the Scotch brand or Magic Slider brand pads. There's many options. And they're not just the stick-on ones that don't fall off all

the time. There's ones that nail in, like in the picture on the right, to the bottom of the chair. And there's also ones that slide onto the table leg like this picture here, and they can help on carpet or hard floors depending on what you need.

Another common problem that people with Parkinson's may have is initiating that movement up and down from the living room furniture. And so you can see—this has worked for several of our Parkinson's patients, to add one of those bed canes, either on their bed or a couch. Canes on the couch to help from standing and to go from seated to standing or standing to seated. That can also help if you're trying to change positions on the couch, if you're laying down on it. And then there's the easy stand and go one on the right-hand picture that has two handles and two sides. It can be used for a couch or a recliner, and you can still use the recliner function, but it provides a more stable surface to push up and stand from your chair. And these actually devices are on mine at Lowe's or Walmart.

And finally another simple home modification is creating non-slip surfaces or reducing slippery surfaces in your house. Most of you probably heard that you should not have loose throw rugs on your floors. And for the most part, they are unsafe for anyone, including pets. A better solution is to have a thin rubber-backed rug that leaves completely flat. And it has a little bit of sticky, rubber backing go here to the floor, but you can also add stick-on or taking the material from different brands and put them on the back of rugs to hold them in place. There's also roll-on grip texture, like in the middle picture, that you can roll onto floors. Read the instructions first, but they provide some traction onto the floor. And we said tape like the Gator Grip, and the picture here and on the right on the shower floor can be placed on stairs, shower tub floors, and other areas to reduce slip. And they typically are better than the bubble section mats that people use, because those are actually a trip hazard. It can roll up under your feet.

Okay. So to summarize, as you can tell, I had a lot of ideas to share with you and there's even more out there, but home modifications are necessary for anyone with a long-term diagnosis. The goal is to increase participation in activity and maintain or improve safety and function. Home accessibility modifications are greatly reduced in stigma over the years, and many modifications to improve safety are best for anyone in society. People with Parkinson's in particular can improve safety and function activity in the home with some of these modifications or others.

If you're unsure what you might need, you can schedule a home evaluation with a physical or occupational therapist and try to make your home adjustments safely and looking into the future and plan for what needs you might have. The right home modifications can make life for someone with Parkinson's and their care partner much better. So thank you for your time. And I have my contact information included. And that's everything.



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