



**The Victory Summit® Virtual Event:
Our Voices, Our Stories: For People with Parkinson's,
By People with Parkinson's
“Everyday Hacks to Live Well with Parkinson's”
Davis Phinney Foundation**

Polly Dawkins (Executive Director, Davis Phinney Foundation):

Our next session is a session on everyday tips and hacks, making living with Parkinson's easier. So, I'd like to invite Tom Palizzi, Heather Kennedy, Jan Grimes, and Marty Acevedo to join us here for this panel discussion. Hi folks. We're waiting for, I think maybe Jan's gonna need some help getting in if one of my colleagues could help her unmute her video or unstop or start her video. There we go.

Jan Grimes (Ambassador, Davis Phinney Foundation):

Yay.

Polly Dawkins:

Yay.

Tom Palizzi (Ambassador, YOPD Council Member, Davis Phinney Foundation):

Hello.

Jan Grimes:

Hi Tom.

Tom Palizzi:

How are y'all doing?

Jan Grimes:

Hi, Heather. Hi, Marty.

Marty Acevedo (Ambassador, Davis Phinney Foundation):

Morning.

Polly Dawkins:

Welcome, welcome. These are some of our most expert people with Parkinson's who have all sorts of tips and tricks and hacks and ideas on how to make living with Parkinson's just a wee bit easier. And to start off, I wanna let you know that there's no need to take notes for this session. We have come up with we will record all of the tips and tricks and hacks that you've come up with, and we will share that after the event. So, sit back and let's turn this over to our wonderful panel. Who'd like to take a start?

Jan Grimes:

Well, I guess we should start with the beginning of our day or for some of us the day has to begin with preparation from the night before. So, I guess I'll start with saying that I always set aside my first dose of L-dopa on the nightstand so that I can take it and get that first boost so I can get going to take my full dose a little bit later. So that's the beginning. How about the rest of you?

Tom Palizzi:

Well, that's a good idea. Great way to get started.

Jan Grimes:

Cause the last thing you wanna do is struggle to get to the bathroom, get your medicine, to get a glass of water, cetera.

Marty Acevedo:

I do a little bit of stretching before I get up. Just a little, you know, stretch my legs, go side to side, because I have some lower back issues. So that really helps me to not, to get to the bathroom. Cause I don't, I stumble when I get outta bed, so I can walk.

Jan Grimes:

Yeah. Yep. Well, and I'm sure we all take safety precautions in the shower with, you know, proper flooring and all of that. But when you get out of the shower, I have a terrific thing that I use to help dry my hair and I'm gonna show it to you right now. It sits on the bathroom counter and it's got a goose neck and a clamp that holds my hair dryer. Wow. So, all I have to do is, I can telescope it up higher or lower and then I just sit underneath it and blow my hair dry. It's really great. I'm sure there's some other uses for this as well.

Tom Palizzi:

Yeah. Well, I have that problem with, when you have hair like mine, I don't worry too much about blow drying. I'm more like blown away.

Marty Acevedo:

Yeah that's why the short hair.

Tom Palizzi:

When I get up in the morning, one of the first things I do is I march, I do marching steps just to get my legs loosened up and similar to stretching out and that type of stuff, a little bit of that maybe, maybe a forward fold, something along those lines just to get my body loosened up a little bit.

Jan Grimes:



Yeah. Have you ever been in a bathroom away from home without the proper bars and handles? I do travel. I know these are not always the most secure, but they work in an emergency. These are the suction cup handles that you can put on the wall of a, you know, bathroom that you're not familiar with. And it has helped me in a few cases get up when I would...

Heather Kennedy (YOPD Council Member, Davis Phinney Foundation):

I'm not to the bathroom yet though, Jan. When I first get up, I'm still rolling around in the bed. You're way ahead of me. I just learned so many things from you. Thank you for the tips. I'm gonna ask you about that equipment that you showed us later. But I'm still rolling around in bed back and forth. And I take these giant steps and I picture lines on the floor so that I don't fall to get to the bathroom, highly recommend doing that, roll around so that you can actually use your momentum to hop out bed by pull yourself upright and then you can say score.

Jan Grimes:

Are you wearing satin pajamas?

Heather Kennedy:

What's that?

Jan Grimes:

Are you wearing satin pajamas?

Heather Kennedy:

I'm usually not wearing pajamas when this happens. So, I look really crazy but see I'm usually alone.

Jan Grimes:

Satin helps me slide around better on the bed.

Heather Kennedy:

Oh, okay. Another tip. Thank you.

Tom Palizzi:

Yeah. Flannel on flannel doesn't cut it.

Heather Kennedy:

Oh no. Yeah. And none of those blankets that are heavy, the gravity blankets or whatever, those are awful.

Tom Palizzi:

Yeah, I can't do those either.

Marty Acevedo:

Yeah. They can be helpful for people with restless leg and that type of thing, but they're not for everyone.

Jan Grimes:

Do y'all have trouble getting the fingernail clippers to stay in your hand?

Heather Kennedy:

Oh yeah.

Jan Grimes:

I have taken mine and wrapped it with medical bandage tape.

Heather Kennedy:

You're amazing.

Jan Grimes:

Well, it just, it helps me grip it. So, my hand doesn't slide and I can actually cut my fingernails myself, so.

Heather Kennedy:

Jan, I'm kind of amazed.

Tom Palizzi:

Me too.

Heather Kennedy:

What about you, Tom? Do you have any tips for things like the hygiene in the bathroom stuff?

Tom Palizzi:

Well, you know, when I get up in the morning, I usually don't shower first thing, I shower a little bit later on, either later in the morning or early afternoon, because in the morning I'm just not stable enough to trust myself in the shower at this point. And then again, after about an hour, when I'm ON, good, things are moving along then, you know, things are moving better and ...

Heather Kennedy:

So timing...

Tom Palizzi:



Timing, timing is everything, you know, preparing the night before for your day, that's coming, you know, what am I gonna wear? You know, pre-buttoning my shirts so they're all set to go. Things like that. So, yeah, it helps.

Jan Grimes:

Sorry, go ahead, Heather.

Heather Kennedy:

I was just gonna ask Marty about the bathroom part. I just learned so many things from you, Jan. I'm amazed right now. Is there anything that you do that helps you get through that part?

Marty Acevedo:

Yeah, I use an electric toothbrush in the morning. It's easier to do that, to get that part of the morning going. And I have a little routine and if I vary from that routine, I invariably forget something. So, I stick to my plan, and you know, go to the restroom, put my contacts in, brush my teeth, take my meds, and then shower. And if I don't follow that regimen and I forget to take my meds or whatever else happens. So, I'm pretty good in the morning. And that shower first thing in the morning really helps ease of the aches and pains from sleeping.

Heather Kennedy:

Jan, I wanna hear what else you've got there.

Jan Grimes:

Well, I have quite a few things on the table here that I'll show you as we go by, but if I have trouble, for example, getting some shoes off the shelf in my closet, I have this wonderful grab-it.

Heather Kennedy:

Got one, highly recommend.

Jan Grimes:

I carry it around with me a lot, just so I don't have to bend over to pick stuff off the floor cause that's difficult for me right now. So.

Tom Palizzi:

Yeah, for some reason I used to be taller and I'm no longer able to reach the top shelf. So.

Jan Grimes:

Yeah. Yeah. Well.

Heather Kennedy:

And careful what you stand on too. If you're going to be doing things like changing light bulbs, don't do it alone like me, just trust me. The sight gags are not worth it.

Jan Grimes:

I've got a really bad knee. So, I have a hard time getting around as it is. So yeah, I'm not gonna get on any step ladders or anything.

Tom Palizzi:

Yeah, speaking to the electric toothbrush, I typically brush my teeth three times a day now instead of just twice a day, like I used to, because sometimes in the morning I'm not quite as adept at handling the toothbrush. I usually get cleaned up first, so to speak, and then brush heavy, or more thoroughly, a little bit later on in the morning when I've got the opportunity to really take control.

Jan Grimes:

I fully endorse what Marty has said about the electric toothbrush. My Oral B is great.

Tom Palizzi:

Yeah. I forgot how to brush without an electric toothbrush. So.

Jan Grimes:

It's certainly a lot more difficult. Well, and by the time I get to the kitchen, can we move to the kitchen?

Tom Palizzi:

Oh yeah.

Polly Dawkins:

Before we do, Jan, I've heard folks talk about taking a tennis ball and putting a slit in the bottom and the top and then putting the toothbrush in so that it's a much bigger grasp and it's easier to hold your electric toothbrush or your other toothbrush.

Jan Grimes:

Great idea.

Heather Kennedy:

And can I mention that Davis has written ladders. Davis, do you mean a bed ladder to pull yourself out of bed or do you mean a ladder to get something out of a cupboard? Cause I like both of those things.

Polly Dawkins:

My guess.

Heather Kennedy:

And the water pick. Yes. Anne says water pik. Love the water pik.

Tom Palizzi:

Yeah. I'm prohibited from climbing on ladders.

Heather Kennedy:

But Tom, your oral hygiene is phenomenal.

Jan Grimes:

Look at that smile. Great. Great.

Heather Kennedy:

To get up higher. Yeah. That's what kind of ladder, but there is something called a bed ladder, just so you guys know you fasten it underneath your mattress or between your, you know, your box spring, your mattress and you can actually pull yourself up, if you have some trouble getting out of bed. For those really hard days, I've also started using canes and walkers around the house because I got tired of crawling to the bathroom. I wanted to have some dignity, even if I was alone. But I like to picture the marks on the floor. Remember you can trick your brain by standing there and gathering yourself and getting your body moving. That's why these smoovey rings are so great. I'll show you those in a minute, but sort of getting your body moving ahead of time by just standing and looking at your feet and where your arms are, cause your brain doesn't know where they in space, then get yourself moving. And that applies to everything. Not just the bathroom in the mornings.

Tom Palizzi:

Absolutely.

Heather Kennedy:

That was something I just wanted to mention before we moved on.

Jan Grimes:

I just recently got a pair of walking sticks.

Heather Kennedy:

Excellent.

Jan Grimes:

And I'm getting used to them, but I feel much more secure walking with them. Otherwise, I am using a walker all the time, but the walking sticks I can use too.

Heather Kennedy:

And if your partner bothers you, you can hit 'em with them.

Jan Grimes:
Great weapons. Right.

Polly Dawkins:
Jan, you were gonna transition to the kitchen. You've gotten up. You've successfully or tried to get dressed and used your hacks. Tell us about your kitchen ideas.

Jan Grimes:
Anybody wanna start?

Tom Palizzi:
Oh, you know, I tend to buy yogurt in bulk these days instead of buying the little tubs because it's just, it's easier for me to get that in and out of the tin and peeling stuff off and just making that process easier works really good for me.

Heather Kennedy:
Yeah. Who designs those? There's no tab anymore. I end up taking a knife and fighting with everything.

Jan Grimes:
Somebody in one of the earlier groups, the pinching and pulling something apart, I mean, as strong as my hands are, I cannot pull like a granola bar package apart. They're harder than ever, but, anyway.

Marty Acevedo:
Yeah, we're not allowed to have sharp knives in our house. I tend to slice myself.

Jan Grimes:
I have a hack for that, Marty.

Marty Acevedo:
OK.

Jan Grimes:
Do you know what this is? It's a shield. You hold it against your cutting board and your, your vegetables are back here. You hold it. And then your knife goes like this while you slice. So, you can't get to your fingers.

Marty Acevedo:
Yeah. Another good idea for that is to buy pre-chopped or diced vegetables at the grocery store because it, you know, it's not that much more expensive and it's certainly a lot safer, at least in my house.

Jan Grimes:
Right.

Heather Kennedy:
Or chainmail gloves.

Jan Grimes:
Yeah. I like to keep cause sometimes double sets of utensils. I have an island of the middle of my kitchen and it's really a pain for me to have to walk around the island all the time to get things. So, I have a little, you know, pitcher of utensils by the stove and one by the sink. So, they're within one or two steps rather than going all the way around the island. So, I also have a sewing kitchen hack. You know how you always have trouble getting to a towel perhaps. Well, I make something called a kitchen boa. It's not quite as glamorous as a feather boa, but it is a bit of a scarf with towels at the end.

Heather Kennedy:
Love it.

Jan Grimes:
Where you can wipe your hands or you can go to the stove and pick up a pot.

Heather Kennedy:
This is amazing.

Tom Palizzi:
Do you have those in like a light tweed?

Heather Kennedy:
Yeah. No polka dots. Tom, get the polka dots.

Jan Grimes:
I make a billion of, no not a billion, but lots of different colors. Team colors. Send me your request and I'll make you one.

Heather Kennedy:
Brilliant.

Marty Acevedo:
Yeah. I get stuck in the corners in my kitchen sometimes where I just freeze. And so like Heather said, I just do some head talk and talk myself out of it and get moving again. And then



moving laterally is a challenge for me, like going across the kitchen cause I have a galley type kitchen. So, I have to think ahead and plan ahead to get out of that freezing mindset.

Heather Kennedy:

Our agility is affected and it's really, really important that we remember that we could easily fall if we try to hurry, especially around the kitchen or the bathroom, does everybody have mats that you can stand on that are tethered to the floor? Don't buy rugs unless you can tether them. Trust me from experience.

Jan Grimes:

Yeah. That's very true. Our kitchen floor unfortunately is a brick surface, which is a little bit bumpy, but my husband has made me something to help me get around the kitchen when my legs are tired and I don't wanna stand there. I don't know. I'm gonna try to help you see this.

Heather Kennedy:

This is great.

Jan Grimes:

It is a stool that has been put on a dolly kind of gizmo.

Heather Kennedy:

I want one.

Jan Grimes:

And the seat is kind of curved, like a saddle almost. Can you see that? So, I can sit on it kind of lengthwise like I'm sitting on a horse and then my feet just paddle around the kitchen. Once we get the floor a little smoother, it'll work better, but it works great. Two of the wheels swivel and two of the wheels stays straight. So.

Tom Palizzi:

Perfect.

Heather Kennedy:

Jan, we have to market this.

Jan Grimes:

My kitchen pony.

Tom Palizzi:

I think that that helps a lot, especially in the case of like freezing cause I'm always, I get stuck a lot in the morning and at night when I'm low on medications, but to get beyond the freezing steps or get my steps moving again, what do you guys use? People use mantras. I use like a

reset step where I, you know, stop, calm down, then move forward with a marching step, something like that.

Jan Grimes:

My specific reset. I usually, I would be with my walker, but I put my weight back on my heels, cause by then I've usually been up on my toes, put my weight on my heels, take a deep breath and just say left foot go. And then I take an intentional big step with my left foot. And that usually gets me going.

Heather Kennedy:

I have an idea for everybody. You can put this song on. You can tell by the way I walk my walk, I'm a woman's man. No time to talk. Or anything with a beat. And then you start moving to the beat. Pretty soon you're walking out the door. It really works. I don't how it works. Right. Now you got an ear worm too, right Tom?

Jan Grimes:

You're lucky. We've also been at parties where, you know, crowds are bad, and so if I would freeze somewhere, I would probably just end up turning around to see who I knew and start talking with them. Since I wasn't going anywhere. So. Make it look like I intended to stop, you know?

Heather Kennedy:

Right.

Marty Acevedo:

Yeah. Crowds are tough. That's when I get really nervous and anxious, because I feel like I'm gonna stop, just freeze in the middle of the crowd and get trampled. So. I developed strategies. I do a lot of planning in my head ahead of time and I have plan B and C and D and I just figure out ways to avoid the crowds, like leaving a basketball game or something, we'll go a different way or up some steps and then around and about. And we go everywhere early.

Jan Grimes:

It's important.

Marty Acevedo:

To avoid that crowd. Yeah.

Heather Kennedy:

Marty, do you take a cane with you as well? Kevin Kwok says whenever we're in public and just in case you can take a folding cane.

Marty Acevedo:

That's a good idea. Great idea.

Jan Grimes:

Yeah.

Marty Acevedo:

Yeah. I tend to freeze moving laterally too. So, like going down an aisle of an auditorium or on a plane getting to the window seats, I always ask for the aisle seat so then I don't have to move laterally and get frazzled and it helps.

Jan Grimes:

That's great. Does anybody have difficulty if they're having any dyskinesia? You know, sliding around on the chair or in the car or anything like that? I do. When play the piano and if I'm sliding around, I need to do this. This is a rubber thing you put underneath your rug to keep it from sliding. Well, I put it on the piano bench and it keeps my behind on...

Heather Kennedy:

Highly recommend those everywhere. Yes, yes, yes, yes. And in the shower, don't forget to get that mat, you know, that's non-slip.

Jan Grimes:

That's right. And since we're talking about how to keep things in place, when I go to a restaurant, I take one of these little, they're like little clothes pins, but they're for sewing instead of straight pins to clip my napkin to my garment, my dress or top whatever I have. Otherwise, I'm always picking it up off the floor and that doesn't look very good.

Heather Kennedy:

Oh, like when you're eating lobster, like a bib.

Jan Grimes:

I don't clip it that high, I clip it in my lap, but.

Marty Acevedo:

Another tip for when we're out and about, is to get that handicapped placard. Ask your doctor for a referral, to fill out the form for you. It's not a stigma related to it, it's just common sense and it helps. And even if you don't need it, you'll get some exercise walking a little bit, you know, you don't have to walk as far to get to places. And it's easier to get in and out of the car, if you're in a handicapped spot.

Jan Grimes:

I remember when I got mine, my doctor said, or I said, oh, just make it temporary. He said, he looked at his nurse and said, no. Write permanent.

Tom Palizzi:

Yeah. You know, and it helps, like you said Marty and not just the mobility factor, but getting in and out of the car can be really a challenge. And like the car, I had a car before that the door hardly opened wide enough to get in and out. So, I need to have those doors wide open. And you just can't do that in some of the tight spaces in suburbia. So that's a good thing. Another thing about when, if you're looking for a car or if you're gonna be looking for a car, I really look seriously and hard at two different ways to get in and out of a car. There's the fall in and climb out for the low car, or the climb in and fall out of like an SUV. It's easier for me to climb in and fall out of the car so to speak than it was for me to get out of a sedan. I, you know, grabbing onto the doors, trying to wrestle myself out. So that's just a something that I looked at. So whenever, when we went car shopping, that's all I looked at was how easy it was to get in and out of the car.

Jan Grimes:

That's very important. But I also exercise my upper body because I'm kind of scrawny otherwise. And I know that I need as much muscle as I can to get myself up and outta places.

Heather Kennedy:

Right. We weren't doing pull up and boxing for vanity. This is survival 101. Tom, when you arrive at the Parkie awards and you get out of that limo, I'm gonna be watching.

Tom Palizzi:

Well, you're getting outta the other side, so...

Heather Kennedy:

Right, right. Cool.

Jan Grimes:

Cool.

Polly Dawkins:

You mentioned exercise, your arms and all, do you all have any hacks to help you through your exercise routines?

Heather Kennedy:

Oh yeah. Anger, rage, disappointment. No, just kidding love. But seriously, it's really easy to get a pull up bar or to get something that you can punch that's not human or too hard. You know, the bags are very easy to install now, or you can just put a pillow against the wall and just be into the light punching. Also just basic pushups, a light set of weights, very accessible stuff. Yep. You can even lean on a chair and do those back of your arms, there's so many different exercise you can do, but definitely go to the experts for that.

Tom Palizzi:

Yeah. And there's a lot of fun exercises to do. Like you just pointed out there, Heather, like working on your triceps on a bench versus a, or a chair, versus some piece of equipment along those lines. One of the things that I have that really is very valuable is a, I'm not sure if I say this right. A Bosu ball or Bosu ball. It's just, it's sort of a half dome and it's filled with air and I stand on that for about five to 10 minutes a day or maybe every other day, more realistically, just to keep my balance good and all you do is stand there, you stand close to the wall, so, you don't wanna fall off of course and they're hard to fall off of, but just concentrating on standing there keeps my legs and my core more strengthened, but it also really helps with my balance. I'll notice if I haven't stood on it for a while. My balance starts to go a little south on me. So, I run back to the Boso ball and it works great.

Marty Acevedo:

Yeah. I have a little ball and a big ball. The ones that you sit on and that helps with balance. The other one, I put between my legs just to exercise my adductors and abductors when I'm on zoom calls or whatever. And then I have, a colleague and I developed a program where it's a web-based program for exercise. And we have coaches. And it's all on an app, cause if I'm not held accountable, I won't do it. So, I have to change those red boxes into green boxes every day, and that's a real motivator to keep me exercising and doing what I need to do every day.

Heather Kennedy:

And make sure you keep medical scissors around the house too. The kind that you'd cut off a cast with that are rounded because those are invaluable. Another thing we mentioned before were these great things by human gear, these are the, you know, pill cases that you can open in one hand, they're a heck of a lot easier than opening these and they just kind of pop open. Yep. We all have em.

Tom Palizzi:

They come in all sizes.

Heather Kennedy:

Right, they come in all sizes and shapes and you can just kind of pop 'em open, one hand.

Jan Grimes:

Wow.

Tom Palizzi:

Thanks Polly.

Jan Grimes:

I don't have one of those. I've gotta get one.



Tom Palizzi:

Yeah, they're great. I've got them all over the house.

Heather Kennedy:

Jan, you've created so many great things. What other rooms or activities can we cover for some hacks to help people get through stuff?

Marty Acevedo:

Well, I don't think any of us should stop traveling if that's something that we enjoy doing. But there's some things we should think about. Again, planning ahead, but if you're in an airport, ask for that wheelchair, I mean, it'll get you through TSA quickly and it'll get you to the gate and you can get on the board easily and early. So that's helpful. And then, and obviously, get the TSA precheck, if you can, or the CLEAR.

Heather Kennedy:

Yes.

Marty Acevedo:

If you're able to.

Tom Palizzi:

That helps so much. You bet. And boarding a plane earlier, you know, you can ask for early boarding privilege or have it put into your profile when you travel cause it's so much easier to get on a plane when you're not under pressure, milling people behind you. And especially if you're flying, like Southwest, where it's dogs eating dogs, trying to get onto the plane. So, get on, get your luggage put away. And you can sit down before the mob comes on. So.

Jan Grimes:

Right.

Marty Acevedo:

Check your bags. You don't wanna have to be dealing with putting something in an overhead bin. It's, that's just, I'm always fearful if I do that, that the bag's gonna fall on some guy's head.

Jan Grimes:

Pack lightly, you know, we always pack more than we need.

Heather Kennedy:

That's huge.

Jan Grimes:

May I show something else that I made?

Heather Kennedy:
Please.

Jan Grimes:

For people, women, for much worse case than we are, but for women who can't open purses with buckles, buttons, zippers, et cetera, I make Japanese knot bags. And a knot bag is simply, it's simply a bag that has two loops. Long, short, no zippers, no buttons. Just the bag, you know? And then you just put the long through the short and it's and long handles, it can be a cross body or it's just a shoulder bag, but you know, they look like this. I've given away about a hundred of them so far and the ladies just love them. So anyway, Japanese knot bag, it's not my invention, but I do make them.

Heather Kennedy:

I was just writing bags and containers that are stiff, that stay open while we're filling them. And while we're getting things out are invaluable.

Jan Grimes:

Yeah and being able to see what's in it. You know, sometimes things get lost because it's black inside the bag or something. You can't see what's in there.

Heather Kennedy:

It's like Oscar, the Grouch's can, what are we gonna pull out next? The fire engine.

Tom Palizzi:

Yeah.

Jan Grimes:

Right.

Tom Palizzi:

Does anybody have a solution for when you go into the grocery store and you always forget to bring the bags that you have in your car? Anybody? I always forget. I don't understand that. Just wondering if anyone had a hack for that.

Jan Grimes:

I have found that the baskets they have at the front of the store, you know, with the little two wire handles that fits perfectly on my walker. It goes right down between the handles onto the seat. And so that becomes my grocery cart.

Tom Palizzi:

Perfect.



Heather Kennedy:

And for those of us, without a walker, Kat Hill made a comment, once, I wish I had a t-shirt that just says I'm handicapped or I'm disabled, or gimme a break or something along the lines of gosh, slow down people. Everybody seems to be such a hurry. There's people pushing on us all the time. You know, and I used to be one of those people.

Marty Acevedo:

Yeah we have to be patient with ourselves and ask others patient with us.

Tom Palizzi:

Definitely. Definitely the case. What do you guys do for fun? What are your hacks when you're out having fun? We have fun all day every day though, right?

Jan Grimes:

Yeah. It's important to laugh. No doubt.

Marty Acevedo:

You have to have a sense of humor, cause if you don't...

Jan Grimes:

Well, I one time had a woman ask me if my husband knew that I was out because she thought it was awful that I had Parkinson's and was out by myself. He said, does he know you're out?

Heather Kennedy:

You're like, I dunno, he doesn't know a lot of things. Keep him guessing, right, Jan?

Jan Grimes:

Yeah, well, you know, I feel that it's our duty to try to educate people. And if I can educate somebody once every day, you know about Parkinson's just what it's like, I'll feel that I've done something good. I had a gentleman in the grocery store one time, see me shuffling behind my cart. And he said, oh, I'd love to learn to dance like that. And I said, oh, you have to have Parkinson's to dance like this. And then he was all embarrassed. You know, I said, no, no worries. This is just part of the deal, you know? So.

Heather Kennedy:

I wish you lived by me.

Jan Grimes:

I think we would have a good time.

Heather Kennedy:

Sometimes I come off a little bitter though. Like people will assume that I'm drunk, which used to be true on occasion. Right. But now I just say, you know, even if I was, alcoholism is, you know, is a disease as well, you know, but this happens to be a neurologic disease. And so, I just kind of pause, like, you know, be kind, you know, we never know. It's best to ask. But you know, I try to make a joke about it too.

Jan Grimes:

Yeah. I won't even call it a disease anymore because I don't wanna be ostracized as being sick, you know.

Heather Kennedy:

Good point.

Jan Grimes:

I'll say it's a condition and I've got under control today. Today.

Heather Kennedy:

Language matters. Good point.

Marty Acevedo:

That's very true.

Tom Palizzi:

I just refer to Parkinson's in general, I just, I totally drop the word disease. It really doesn't matter. I have Parkinson's and people know what you're talking about. It's not a big secret, so.

Jan Grimes:

That's right.

Tom Palizzi:

But for exercising, I've always been quite active. I've been a cyclist for most, all my life. Not a competitive cyclist, but just a, you know, I just ride my bike a lot. But some of the things that I did, I used to use Parkinson's as my excuse to stop doing some of those things. But last year I decided to change that around and try to talk myself back into doing those things that I enjoy doing. So, I got back on a two-wheel bike cause I had gone to a recumbent trike and I still love my recumbent trike. But again, if you have balance issues or if you're trying to ride in an area where there's traffic, for example, I never have to clip out when I'm on my trike. So, I can just sit there, pull up to the light, press the button, or just wait for it to turn green and take off again. It works really well. And you know, I go riding with my friends a lot and we have a good time, and I can keep up with them. So, you can look at those things and they also make e-bike versions or electrified versions of e-bikes or rather recumbent trikes, two wheels up front one in the back.



Marty Acevedo:

We have a tandem electric bike cause I can't manage all the multitasking that it takes to ride a bike. So, my husband is in front, I'm a stoker and we go my pace, which is pretty brisk at times, but it has an electric assist to get through those intersections and up those steeper hills.

Heather Kennedy:

Can anyone here keep up with Davis Phinney? Polly, maybe.

Tom Palizzi:

Only when he doesn't have his battery in his bike, he took his battery out of his bike the day, I had to thank him for that. I still had a hell time trying to keep up.

Heather Kennedy:

Well, Tom you're pretty fit.

Tom Palizzi:

Same thing, Polly.

Polly Dawkins:

Yeah. Tom and I have ridden together. It's quite fun.

Polly Dawkins:

I know Marty. You've got so many ideas around some of your hobbies like camping, any, any hacks that you wanna share about camping that make it easier for you?

Marty Acevedo:

Yeah. Camping is not for everyone. We have a class B travel van. It looks like a regular van and parks in regular parking spots. But one of the cool things about it's that you always have your bathroom right there with you, if you need it. So, there's no, you know, stopping and rushing to the restroom when you're on the road. Planning ahead is really important. My husband mentioned to me that they sold 330,000 RVs in the United States last year. So, you used to be able to go out to a park and just, you know, get a spot to park for the night. Now you have to make reservations ahead of time. So, it's helpful to plan ahead. It's tight quarters and you just have to just plan for that and learn how to sidle sideways, to maneuver through a van type situation and then the grounds not always level. So that's really important to make sure it you're very careful about how you're walking, cause tripping is a big deal. And those are the basic ones. Plan, you know, I guess I'm a planner cause I keep using that word. But doing planning ahead, making sure you have the things that you need and as Jan said, pack light. You don't need a lot of stuff.

Jan Grimes:

If I might add a kind of sensitive subject here, you mentioned, you always know where the bathroom is when you've gotta go, because that's, you know, I can get caught so easily and feel



like I have to go right now. I have ordered on Amazon. They're like disposable little urinals for women, but they're, it's paper and it has a towelette inside it that you take out for use afterwards. But the whole thing is disposable and it's great for an emergency. I carry one in my purse all the time.

Heather Kennedy:
What is this called?

Jan Grimes:
Well, it's just a personal urinal for women. It's all covered in plastic, but it's totally disposable.

Tom Palizzi:
It's really helpful for when you're traveling in a foreign country where there's not a bathroom, very readily available. I know my wife has done that in the past and my daughter even. And they had those when, like when they were touring China a few years ago and it really, it totally helps. I know exactly what you're talking about.

Jan Grimes:
It takes a lot of stress off of you, if you know you have an out, you have an emergency, you know.

Heather Kennedy:
Right, and we never miss a chance to go to the bathroom.

Jan Grimes:
I never go anywhere that I don't locate the bathroom first thing.

Heather Kennedy:
Yeah, exactly. You know, and be conscious of others too. Like, excuse me, pardon me? Do you remember the bugs bunny where he is walking over people in the movie theater? That was one of the tricks we did in our Parkinson's bootcamp. You know, also teaching people how to get up when they fall and how to get outta bed and so on and so forth. But that thing where we have to cross over people is really dangerous.

Jan Grimes:
Yeah.

Marty Acevedo:
Yeah.

Heather Kennedy:
Sit by the door, I guess.

Jan Grimes:
Yeah.

Tom Palizzi:
One of the big plugs I put in for exercise in general is not only does it help mitigate your symptomatic or your symptoms rather, most exercises, boxing, cycling, indoor cycling, that type of stuff, but it also helps you stay in better shape or at least some form of better shape. And I tell my cycling class, we do this for two reasons, one to mitigate the effects of our symptoms, but also to stay in a little bit better health because when we do fall, as we will someday, or when we do get pneumonia or a bad cold or COVID or something along those lines, we'll have somewhat better strength to defend ourselves against that or fend that off and recover. Cause that's the kind of thing that gets us in the end is something like that versus Parkinson's so to speak. So yeah, remember you're exercising for more than just, you know, symptomatic mitigation.

Jan Grimes:
And it can make you happy, the endorphins can really affect your mood.

Tom Palizzi:
It helps with your anxiety and depression and those things. So, it's really very good. Really, very good.

Heather Kennedy:
We have to look at that as our main medicine I believe. Right?

Tom Palizzi:
Totally, absolutely.

Jan Grimes:
Absolutely.

Heather Kennedy:
To be flexible and adaptable is really what this is about. You have to have adaptation techniques with Parkinson's. You cannot be in control. There's no such thing. Because Parkinson's becomes the thing that's in control after a while and we just have to work with it. And people say, I'm gonna beat Parkinson's, that's like punching yourself in the face. I mean, I love the idea of it. My ego loves I'm gonna beat Parkinson's, but the truth is I have to work with it.

Jan Grimes:
Have any of you heard this saying I may have Parkinson's, but Parkinson's doesn't have me?

Marty Acevedo:
Right, right.

Jan Grimes:
So.

Tom Palizzi:
Yeah, I think to add to what you said, Heather, being creative too, I think Jan's really showed us that today. That's really cool. Just being creative and thoughtful about how to get around better, how to make things easier. So that's really cool. I applaud you guys.

Jan Grimes:
I have a new hack I'm working on. It's really not in a show you stage, but I have found that a regular hairpin can help me with my buttons.

Tom Palizzi:
Oh.

Jan Grimes:
I put the hairpin around the button and then I put the two ends of the hairpin through the button hold and just pull and it pulls the button right into line with the button hold. So, all I have to do is push it through. I don't have to manipulate the button to get it to the button hole. So.

Heather Kennedy:
Excellent.

Jan Grimes:
Just a hairpin.

Tom Palizzi:
Yeah. Can we get together, Jan, you and I? I'd like to see if there's ways you can help me get my fly tied on the end of my flying rod. That'd be really helpful.

Jan Grimes:
Well, I have to think that my piano practice has helped with some of that. It might help with your fly rod too.

Tom Palizzi:
Yeah. I'm sure it would.



Heather Kennedy:

Yeah. And I highly recommend too singing every chance you get and learn how to communicate with everybody around you, because people can't read our minds.

Jan Grimes:

That's right.

Heather Kennedy:

When we're frozen, you know, or when we're doing, something's happening or when we're not thinking clearly. I got yelled at the other day for being on the side of the road instead of the walking path. Cause I was sort of looking down, focused on my steps and I walked right out into traffic.

Jan Grimes:

Oh.

Heather Kennedy:

So it's like, people don't know what we're doing. You know, they were screaming at me like get out of the road you idiot.

Marty Acevedo:

And it helps to exercise our vocal cords and that can help with swallow down the line too.

Heather Kennedy:

Yes, swallowing.

Heather Kennedy:

I don't want to choke in a restaurant.

Marty Acevedo:

Yeah.

Jan Grimes:

There's an exercise for swallowing. Do you all know it about biting your tongue and then swallowing?

Heather Kennedy:

Tell me.

Marty Acevedo:

Yeah. There's whole programs for speech and swallow. Cause anytime you exercise, you speak or speak loudly with intent, you're exercising those vocal chords, which makes them stronger to be able to protect your airway. Don't risk aspiration.

Tom Palizzi:
That's the key word intent.

Marty Acevedo:
Yeah.

Heather Kennedy:
Someone said yodeling. Parkinson's voice project, yes. Jan, what is the technique that you mentioned? Is it something you can show us quickly?

Jan Grimes:
If you put your tongue between your teeth and bite and then close your mouth and force a swallow and do that 10 times.

Tom Palizzi:
You can feel it work your muscles.

Heather Kennedy:
It looks so good.

Jan Grimes:
But you can, you can really feel those swallow muscles working and you know it's good.

Tom Palizzi:
Yeah, that's a huge, a significant part of Parkinson's is recognizing that it's more than just your outwardly appearing, muscular componentry. It's also the interior stuff too. So makes a big difference practicing things like swallowing and singing to keep your voice, vocal cords strong, all kinds of stuff like that. Big and loud, loud and louder, whatever.

Marty Acevedo:
Parkinson's Voice Project, yeah.

Heather Kennedy:
What do we do with unusual days? For example, my purse was stolen. They took my iPhone, my DBS controller. Someone had control of my brain, just saying, it wasn't my fault. It wasn't me. I've got an excuse now. But all things considered, what do we do in those cases? We don't have a phone to call someone. What if we don't have a landline? I laid on the floor for several hours one night. I mean, what do we do? Or what do people do when they don't have a



backup? Jan, do you have something on your person that you can call? If you don't have your phone and if we lose our phones, does everybody have tiles on their devices? Apple watch. Good. Okay. What else? Let's keep talking about this.

Polly Dawkins:

I want to take one idea from everybody cause then we need to move to the next session Amy's here for. So, one idea for Heather and the audience about what you do, if you get in that situation.

Marty Acevedo:

Well, I don't carry a purse everything's in a pocket on me. So, I wouldn't, I would hope I wouldn't get in that situation without being able to reach someone.

Jan Grimes:

My apple watch says it appears you have fallen. And if I don't respond at a certain time, it will call 9 1 1. But I can say no, I'm all right. Or I did not fall.

Heather Kennedy:

I need an apple watch.

Tom Palizzi:

And there's apps for that, that can run on the phone as well. But apple watch is really a great solution that's really optimized for that. They've really spent a lot of effort optimizing it for accessibility and specialty uses like that.

Polly Dawkins:

Great ideas. Thank you all. We could go on and we could invite all sorts of ideas from the audience, which we will do, and then we'll share these ideas and it looks like we do need to do a bit of a hackathon on with folks and a shark tank for Parkinson's.

Tom Palizzi:

Polly, we have a list that we made for this and we'd be happy to, I'm sure you can get that from Mel and...

Polly Dawkins:

Yeah, we'll share that after the event. Thank you all for joining us, for your ideas, sharing your creativity, and your struggles.

Jan Grimes:

Sure, it was fun.

Polly Dawkins:



Bye everybody.

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