

**Tips, Tricks, and Products to Manage
Parkinson's Symptoms**
with Jan Grimes
Davis Phinney Foundation

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

Hi everybody. This is Melani Dizon. I'm the director of education at the Davis Phinney Foundation. And I am here today with Jan Grimes. Jan is a long time ambassador for the Davis Phinney Foundation. And Jan, why don't you tell us a little about you and what we're doing here today?

Jan Grimes (Ambassador, Davis Phinney Foundation):

Well, I won't tell you my age, but I have been diagnosed now, I'm in my 17th year. I was diagnosed in January of 2006, and I credit a lot of my wellbeing and living well to the Davis Phinney Foundation because they've taught me so very much. I'm a retired pianist from the Louisiana State University and I still play the piano every day. And that's also part of my good fortune I think.

Melani Dizon:

That's great. Yeah, that's great. So, a couple of weeks ago we had, we held the Victory Summit event and one of the sessions was hacks on how to live well with Parkinson's and Jan had just it seemed a never ending toolbox of hacks. And so, we wanted to invite her back so that she could go through all of her hacks and share with you some of the things that she uses to live well. So, I'm gonna pass it over to Jan and just let you kind of go, I think you're gonna start with the early in the day, and you're gonna move through the day and kind of share all the different hacks that you use.

Jan Grimes:

That's right. I'm going to start with getting up in the morning and of course, needless to say, it's important to keep a good attitude and to exercise. We'll just take those as givens. So, I won't talk about those. All right?

Melani Dizon:

Great.

Jan Grimes:

But first thing in the morning, I always take a half of an L-dopa just to give me a little kickstart in the morning. And then I take my regular dose about eight o'clock, but that's just what works for me.

Melani Dizon:

Okay. So, is this, just real quick, is that, are you, are you taking a half of what would be part of your regular dose? Or are you taking a half in addition to a regular dose?

Jan Grimes:

I am taking a half of a tablet in addition to, but it's early, it's two hours before I would take my regular daily dose.

Melani Dizon:

Okay, great.

Jan Grimes:

So, it is kind of an extra thing, but because of its immediacy or nearly so, I get the benefit of it quicker.

Melani Dizon:

Excellent.

Jan Grimes:

And so I can move around and it really does the trick for me. So, I don't know, you can talk to your doctor about that. But there are several hacks in the bathroom that I wanna share, you know, getting ready is tenuous and it can be dangerous. So, there are, you know, the rubber things in the shower, make sure you've got a textured floor on which to stand, so you aren't slipping, sliding around. I keep my walker with me everywhere I go. And that's just for my own safety because I've got knee problems as well. But speaking of sliding, if I'm trying to trim my fingernails or toenails, the chrome instrument can be very difficult to hang onto, my fingers slide and my grip isn't as strong as it used to be. So, I have wrapped my clipper with medical medicinal tape. If you can see that...

Melani Dizon:

Oh, there we go. Okay.

Jan Grimes:

Yeah. And so that gives me something, my fingers, you know, something to grip and it doesn't slide, it's much, much better. And we were just talking about the shower. I have a hairstyle that of course has to be blown out every now and then. So, I get the help with this gadget. Now this gadget sits on my counter up. It looks kinda like a microphone stand, it telescopes and has a little goose neck here with a clamp that holds my blow dryer.

Melani Dizon:

Oh.

Jan Grimes:

So I can just stand under it or sit under it in my walker, however I wanna do it, but it gives both hands free to do what I have to do with my hair.

Melani Dizon:

So how do, like, where did, is this something you made up from something that's used for something else or is this an actual hair blower stand?

Jan Grimes:

This is actual hair blower stand that I found of all places, of course.

Melani Dizon:

Great. Okay.

Jan Grimes:

Yeah, but since the time I bought this, now they make, and I don't have it out here right now, but they make a handheld blow dryer wand that blows and the brush twirls at the end. So, it does the job of the blower and the brush in one unit.

Melani Dizon:

So, you're not actually holding it at all. It's doing it...

Jan Grimes:

You hold the just of blower, but the end of it turns...

Melani Dizon:

Oh, okay.

Jan Grimes:

You hold a button that makes it turn. And so, it does the action of rolling it. It's incredible. My sister gave that to me.

Melani Dizon:

That is a good gift.

Jan Grimes:

Now, if I'm, okay, if I'm heading then up to breakfast and depending on what I'm going to do first in the day, I have a wonderful apron that my sister made. It has pockets, and I load it with things that I'm gonna need. Here are some hair clips. Here's a headband, here are my gardening gloves if I go outside, a pair of reading glasses, you know, we never know where those are gonna show up or be lost. And I normally would have a little clipper in there too, because when you go outside, you almost always end up clipping something. So that's what I would, then head to the kitchen and be ready for the day. In my kitchen...

Melani Dizon:

Wait, do you wear that outside too, like when you're gonna head out for the day, so you just wear it all day?

Jan Grimes:

I don't go to the store in it or things like that, but if I'm gonna be working in the yard or something like that, I would have it with me. Let's see, but yeah, it's washable, throw it in the wash. In fact, I had to dump the dirt out of this one today because it was, had been in the yard a good bit lately. We've had nice weather. So, heading to the kitchen, I have a big island in the middle of my kitchen, and I don't walk always very well first thing in the morning. So, getting around the island is a challenge. So, Bill and I have a deal and it's great. He is my legs in the morning and often when I'm cooking, either my sous chef or when we empty the dishwasher, I'm on one side of the island, he's on the other. So that things that have to be put away, I can do on my side. He can do on his side. It saves so much walking.

Melani Dizon:

Oh, that's great.

Jan Grimes:

And likewise, with cooking, I keep duplicate utensils on the island side and then on the stove side so that I don't have to go around the island to get a tool.

Melani Dizon:

Oh, that's a great one.

Jan Grimes:

Clippers, flippers, things like that. Nothing, no specialized tools or anything.

Melani Dizon:

Do you have any, I've heard people have like stations in their kitchen where I have a coffee station or a tea station and everything is just there. So, I don't have to go anywhere else.

Jan Grimes:

Actually, we do. If, well, I was gonna have Bill walk over and show you, but we have a coffee station with an espresso and a Keurig. And then we have the cups up above and the coffee in all available, all the pods. So that's right there. And then next to that is the station where I keep all my dishes and they're on open shelving. Next to that is my mixer. I keep it on the countertop because it's so very heavy, but it's shoved in a corner, and it's covered with a cover that I made. And then if you open the cabinet doors above it, it's all the flowers, sugar spices, everything. So that's my baking station.

Melani Dizon:

Nice.

Jan Grimes:

Yes. And then I keep my power tools in a cabinet under the island. So, if I'm going to make hummus or something that I need to use a processor for, it's right there and it's ready to go.

Melani Dizon:

Great.

Jan Grimes:

Let's see. Oh, my most important thing. I sew a little bit. So, I make kitchen boas they're called and I'm sure everybody knows that a boa has the connotation of being a glamorous feathered, you know, thing like that, but this is much more practical. This is a scarf made out of 100% cotton fabric with towels, but it's actually one towel cut in half and then each half sewn to the ends of the scarf and to be worn in the kitchen because you know how it is when you're looking to wipe your hands, or you've just broken some eggs, you've got stuff all over your hands. Then you've got something to wipe your hands on right in front of you or it can be used to lift up a hot pot.

Melani Dizon:

Oh yeah.

Jan Grimes:

And if it's clean, you can use it for dry dishes. So.

Melani Dizon:

Right, right. That was funny. So, when we were during the Victory Summit event, this was one of those items that everybody was yelling in the chat. I want one, I want one, where do I put my order in? So very, very interesting. So that's a great thing. You just kind of buy some material for the piece around your neck, and then you can cut a towel in half and just sew it. You can use a sewing machine, or you can hand sew it, have someone there to sew for you.

Jan Grimes:

And I'd be happy to put together some very elementary and skeletal instructions if somebody wants that.

Melani Dizon:

Oh, I am sure they would love it.

Jan Grimes:

You can vary it just about in any way possible.

Melani Dizon:

I want one of those myself, like those are perfect.

Jan Grimes:

They're really great. I have several that I use. So, after breakfast, well, let's see, okay. After I usually play the piano for a few minutes before I get going, because I find that that small motor work and getting my mind going, it's all really, really helpful. I had a wonderful weekend this past weekend with my neurologist who many of you know is a performing partner with me. She plays the clarinet, and we had a rehearsal on Sunday and just playing the piano that much that day, I just had a really great walking day.

Melani Dizon:

Oh, wow.

Jan Grimes:

I don't know how that helps me, but it did, something did, it was really a great day.

Melani Dizon:

That is great. Have you had any issues with dystonia or, you know, bad rigidity in your hands and or is that not been an issue?

Jan Grimes:

I have dystonia or no, no dystonia, dyskinesia occasionally. Now it's been much better recently for whatever reason. I don't know.

Melani Dizon:

Maybe there's some research with piano and Parkinson's.

Jan Grimes:

Well, there is actually an entire new field being opened up called neuroaesthetics. Have you heard of it?

Melani Dizon:

No.

Jan Grimes:

Neuroaesthetics. And it deals with how the arts, music in particular, affect the brain and Parkinson's.

Melani Dizon:

And symptoms. That is really interesting. Okay. Great.

Jan Grimes:

It's very interesting. So, but the dyskinesia leads me to another thing because when I'm practicing the piano and if I have any dyskinesia, now this can be used any in any case, but you know, anyone who has dyskinesia notices that they slide around on their chair or bench or whatever they're sitting on. So, I use this, it's used for rugs to keep them from slipping, but I put it on my piano bench or organ bench or whatever I'm sitting on so that I don't slide off, because literally the dyskinesia can be pretty severe sometimes. And you end up really sliding around.

Melani Dizon:

Oh, that's a great one. That's great. Those are also you know, people sometimes use 'em in their drawers, right? Like under like a kitchen organization thing, you put 'em under those drawers. Yes.

Jan Grimes:

I think it actually might be shelf liner too.

Melani Dizon:

Oh, shelf liner. Okay. Right, right.

Jan Grimes:

I think that's what it is too. So, but then I've already been accused of dancing under the piano when I have dyskinesia because my legs were going to and fro, so I keep a theraband in my music bag and I tie my legs together above the knees with this theraband. And so, my feet are still functional on the pedals, but my legs don't separate and go sprawling all over under the piano.

Melani Dizon:

Oh, what a good idea.

Jan Grimes:

So, can you picture that?

Melani Dizon:

Oh yeah. Okay. Yeah. And does it mess you up at all?

Jan Grimes:

No, actually it's a very stabilizing feeling because...

Melani Dizon:

Okay. Yeah. It's sort of the equivalent of when people put their hands in their pockets, right?

Jan Grimes:

Yes. Yeah. It's a security feeling.

Melani Dizon:

Yeah. Cool.

Jan Grimes:

They have more than one use.

Melani Dizon:

Yeah.

Jan Grimes:

You could say. Okay. One thing I did not mention in the kitchen and of course this can go for being out in public as well. But when I go to a restaurant, I'm constantly dropping my napkin on the floor and it's very embarrassing to be leaning over, picking it up all the time. So, I have these little, they look like little clothes pins. Oops. Where's my camera?

Melani Dizon:

Yeah, no. There we go. There we go.

Jan Grimes:

Looks like a little clothes pin, and I use that to clip my napkin to my garment.

Melani Dizon:

Oh.

Jan Grimes:

You know, it's very discreet and it's not obtrusive in any way, so. But it saves a lot of embarrassing bending over like a kid, you know?

Melani Dizon:

Right. Well, you're assuming the kid's gonna pick it up. So that's...

Jan Grimes:

Oh, well that's true. Or use it.

Melani Dizon:

Right.

Jan Grimes:

Okay. One other thing in the kitchen I have found that is very helpful is to wrap a rubber band around a lid. Now I have a purple rubber band wrapped around this, but it's the same thing as a

rubber gripper, but see, it makes it so much easier to get the lid off because you can actually really grab that rubber.

Melani Dizon:

Right. That is a great idea.

Jan Grimes:

That's probably not a new idea anyway. Okay. So, onto, okay to finish at the piano. After I've played a few minutes on that I will perhaps do some laundry and I just wanna say to anybody who uses a walker, that it has so many more uses than just to help you walk. I use my walker and I carry stuff in it everywhere I go. You know, I used to, although we haven't done it so much recently is carry coffee to Bill in the bedroom because I had a tray that fit precisely on my walker and it was great to carry, you know, just a small snack or something. But I almost never make one trip the end of the house or back without something in my walker, you know, and it's so much easier to carry clean, hung laundry, just drape it over there and go to the bedroom.

Melani Dizon:

Right.

Jan Grimes:

And so that's very helpful.

Melani Dizon:

Did you have to do a lot of sort of shifting around your house to, so that you can get your walker around everywhere?

Jan Grimes:

Actually, no. The only place a room we modified when we moved into this house three years ago was the master bathroom because the shower door was about this wide and it was, it was terrible. But Bill also, and I'm fortunate that he's such a handy carpenter. He has made small little ramps where the doorstops are, you know, maybe just an awkward couple of inches. So, he made small little ramps, but he has a larger ramp at the front door and going into the garage and then into the patio area, he has a small step platform that splits the distance between the big steps.

Melani Dizon:

Right. Right.

Jan Grimes:

Because step coming out is quite, quite deep. So, this is much safer now.

Melani Dizon:



Oh, nice. That's great.

Jan Grimes:

So, we've done that. Right. So, let's see, I'm thinking... oh, about the walker, some more things. When we go to the grocery store, I use the walker as my grocery cart. Now, you know, those baskets they have with the two metal handles, it fits perfectly between my handlebars. And so that becomes my basket and Bill goes around with the big basket, but at least I have a small one to collect things on and that's just really, really handy. It's so much better than just putting it on the seat...

Melani Dizon:

Right.

Jan Grimes:

And risk it falling off and breaking on the floor, you know.

Melani Dizon:

Right, right. So, this is like, oh, you need to, when picking out a walker, consider all things that you can be able to use it for. Right?

Jan Grimes:

Yeah absolutely. It's really endless. I carry piles of books on my walker, if I'm rearranging books on the bookshelf. I mean, the list just goes on.

Melani Dizon:

Nice.

Jan Grimes:

Let's see... one, this is just a little hack that maybe isn't related to any room particularly, and it's not particularly Parkinson's, it's just a handy thing to do, you know, those little square plastic clips on bread bags.

Melani Dizon:

Yes.

Jan Grimes:

If you save those and use them on rolls of tape, you don't have to then use your fingernail to find the end of the tape.

Melani Dizon:

Oh, that's brilliant.



Jan Grimes:

So, you can just, you know, there you got it and then you take it off and put it at the end.

Melani Dizon:

Oh gosh, I was actually just struggling with a piece of scotch tape, I could not, I probably wasted four rolls around and around trying to get the end. That's a great idea. I'm using that one.

Jan Grimes:

Yeah. So don't throw those little plastic things away. Let's see. Okay. I think I'm about to go to one of my favorite hacks, which again is not, Parkinson's only related, but I've had a lot of fun sewing and giving these away. I've given probably over a hundred of them away. But, I've been fortunate. I have a friend who has a drapery and upholstery shop downtown Baton Rouge. And he gives me his remnants. The first time I went to see him, he gave me six kitchen garbage bags filled with remnants. And so, many, many bags have come from those. And so, the cost is minimal if any, for some of them. But the beauty of these is, and I did not invent this style. It's called the Japanese knot bag, K N O T. They are great because they are a simple bag, and you can make these, I'd be happy to send directions, but it's a simple bag with one long loop and one short loop and you just do this and it's closed. Hence the knot.

Melani Dizon:

Oh, nice. That does not look simple. That looks like I, that does not look simple.

Jan Grimes:

Well, I did ornament this one a little.

Melani Dizon:

With flourishes. Yes.

Jan Grimes:

But anyway, so I have a couple of others. Most of mine are reversible.

Melani Dizon:

Oh nice.

Jan Grimes:

This one has a pocket on the outside.

Melani Dizon:

Oh yeah.

Jan Grimes:



This one is very simple, very simple, but very long, long for like a cross body. But women with arthritis really love these because you don't have to fiddle with the buttons and zippers and things like, and this is my humorous one. He had this great fabric that was this monkey.

Melani Dizon:

Oh, that is great. That is great.

Jan Grimes:

So that was kinda fun too. I have another thing that I use a lot and I would recommend that everybody have at least two of these. It's my grab it.

Melani Dizon:

Ooh.

Jan Grimes:

I use this so much. Bill doesn't know this, but I've used it in the pantry already to grab something on an upper shelf. Something not breakable usually. But it's really great. And I can actually just tuck it in my, the belt of my apron if I'm outside.

Melani Dizon:

Oh, nice. Yeah.

Jan Grimes:

It's like my pistol holder or something.

Melani Dizon:

Great. Is that extendable?

Jan Grimes:

This one is not, it's just, it's probably about 30 inches long, something like that.

Melani Dizon:

Great. You kinda keep one in the kitchen and keep one..

Jan Grimes:

I keep one in the bathroom, the laundry room as a central location. And I keep one in the kitchen, but I try to remember to take it outside with me because we have sticks and little spiky gumballs that fall from the trees and stopping to pick them all up is hard, if not uncomfortable, you know?

Melani Dizon:

Right, right.

Jan Grimes:

So, this makes it a lot easier.

Melani Dizon:

Nice.

Jan Grimes:

Okay. I do have a button hack. It's not as sophisticated as the commercially available one but maybe you should just put this on and I'll button, demonstrate, well, anyway, this is it.

Melani Dizon:

Okay.

Jan Grimes:

So, the commercially available one has a big rubber handle and everything, but if you don't have one of those or you can't afford to get one, you can use a hair pin.

Melani Dizon:

Like just a Bobby pin.

Jan Grimes:

Yes. A Bobby pin. And what you do is, you know what, I'm gonna put it on. Okay. Bill's gonna put it on. So let me just turn it to Bill.

Melani Dizon:

Hi, Bill.

Bill Grimes:

Hola.

Melani Dizon:

Thanks for being our model. This is great.

Jan Grimes:

If you would just come a little closer so we can see. All right. Okay. Can y'all, can you see that?

Melani Dizon:

I can, yes.

Jan Grimes:



Okay. So, all you do is take the Bobby pin, push it around the thread of the button. Pull it and turn it around.

Melani Dizon:
Okay.

Jan Grimes:
And then push it through the buttonhole and...

Melani Dizon:
Oh. Oh wow. That's perfect.

Jan Grimes:
Yeah. It's much more compact than the big thing.

Melani Dizon:
Right. And I mean, you just can put 'em anywhere. Right?

Jan Grimes:
That's right.

Melani Dizon:
Keep them in your purse, keep 'em in the kitchen, keep 'em wherever.

Jan Grimes:
Exactly. And yeah, absolutely. So.

Bill Grimes:
You're supposed to do the Vanna White thing.

Jan Grimes:
The Vanna White thing. So, you know, even though that's not a new invention, that is a simpler solution than the eight or nine dollar commercial deal. So, I'd like to talk a minute about traveling.

Melani Dizon:
Oh, that's great.

Jan Grimes:
Okay. Even though it's not part of my regular day, but when we do go somewhere, I, you know, you never are sure that you're gonna have disability or disabled modifications in the bathroom room. And so, I one time got stuck in a bathroom in a Wendy's. This was a couple of years ago

actually, before I really had developed some symptoms. But when I would get stressed, it was bad. May I tell the story real quickly? Okay. So, I was in the handicap stall and all of a sudden, I could not get up. I could not make myself stand up. And I was pulling on the bar and everything. And I was, I thought, what am I gonna do? I'm gonna start yelling for Bill in this Wendy's? Well, in answer to my prayer, God sent two women in and one of them happened to be a nurse.

Melani Dizon:
Oh.

Jan Grimes:
And I said, can you help me? I've got Parkinson's and I can't get up. And she was with a younger woman who slid under the door because of course it was locked. She slid under the door, unlocked it, and the two women helped me and I told them they were angels, you know.

Melani Dizon:
Oh yeah.

Jan Grimes:
So anyway, now I travel with this or these, I should say. These are suction cup handles.

Melani Dizon:
Oh yeah.

Jan Grimes:
I know that they are not meant to be permanent for people, because they can come loose, you know, it's possible. But for me they've been very reliable and a great relief if I'm in a situation where I don't have any help.

Melani Dizon:
Yeah. And so those are, those are initially like sort of meant for the shower because they just suction onto the shower, but they will suction onto a bathroom stall or...

Jan Grimes:
Sure. Yeah. That metal. Yeah, absolutely, it will. And it's got, you know, it has a nice thing to lock it down and it's got a good grip. So, it has really come in handy.

Melani Dizon:
That is great. And where did you get those? Just like a Bed Bath and Beyond kind of place or?

Jan Grimes:
I think so, you know, I'm not honestly sure. I've had them a long time. Oh dear.

Melani Dizon:
That's okay.

Jan Grimes:
Decline. All right. Sorry I wasn't expecting that.

Melani Dizon:
That's okay.

Jan Grimes:
Okay. Yeah, I think like a Bed Bath and Beyond, but you know what? Amazon, that's right. Okay. So also, when I travel, I'm always so particular and I know everybody about their medicine. You wanna have it with you at all times and make it accessible. So, I keep it in a little pill box that has just the medicine for that day laid out. And then I have something that has the whole week in it. But a lot of times I might be in a situation where I think, oh, I don't have a bottled water or we have to stop for a drink. So, I carry these little Rubbermaid things with just water, purified water in it.

Melani Dizon:
Oh yeah.

Jan Grimes:
It's leak proof. And I can keep it in my purse for an emergency, you know, it's small.

Melani Dizon:
Right, right.

Jan Grimes:
And I can just drink right out of that. And then I know I can take my medicine.

Melani Dizon:
Right. Oh, that's great. Yeah.

Jan Grimes:
So, it's really, really important, I think. And of course, at the same time, it's important for us to have healthy snacks. So, in the same kind of container, I keep some candies.

Melani Dizon:
Nice. Yes. Never wanna be caught OFF.

Jan Grimes:
No, exactly. And I think that is all the hacks I have today.



Melani Dizon:

Well, those are, that's amazing. I know that I'm gonna create a sheet and we'll, I'll find some links to some of the items. And if you wanna share the directions on those two, the knot and the towel thing maybe.

Jan Grimes:

Oh, sure.

Melani Dizon:

And we can.

Jan Grimes:

I'd be glad to.

Melani Dizon:

We can share those. Well, thank you, Jan. I can't wait for part two and we'll share all this information with everybody here.

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