



**The Victory Summit® Virtual Event:
Our Voices, Our Stories: For People with Parkinson's,
By People with Parkinson's
“Living in the Present, Planning for the Future”
Davis Phinney Foundation**

Polly Dawkins (Executive Director, Davis Phinney Foundation):

Well welcome Amy. Folks, this is our friend Amy Montemarano. If I pronounced that correctly.

Amy Montemarano, JD (Ambassador, Davis Phinney Foundation):

Perfect.

Polly Dawkins:

Thank you. And Amy is gonna lead us through a session on living in the present and preparing for the future. I'm gonna go off video and let you take it away. Thank you, Amy.

Amy Montemarano:

So, I'm gonna start this presentation and I know I'm running a little bit late, so I will make it quick, but I'm gonna start this presentation with a question to ask the audience. And that is, if you had one wish for yourself, for your life, what would it be? What would it be? And if your wish was to not have Parkinson's anymore, I'm completely with you on that. But I ask you, I ask you what happens next? Does it mean that if we don't have Parkinson's anymore, that we have a future that's free from pain and suffering? And of course the answer is no, not at all. We can get diagnosed with something worse tomorrow, right? And that goes for any way that you're going to answer that question. When you spend time wishing and wanting something for your life, it's the wanting, itself that causes a certain amount of pain and suffering.

And it's that wanting, that space of wanting where you lose any little bit of control that you may have had and where those heavy feelings of anger and despair are waiting to descend on you. That's what I've been learning. And in fact, I was listening to a podcast yesterday, the new Brian Grant podcast that had their co-host, which was fabulous. And Brian said, expectation is the path to resentment, which I thought that was a lovely way of saying that, you know, wanting something different for your life is itself causing you pain and suffering. And when I start to understand that, and when I start to incorporate that into my life and start living in the present, rather than getting distracted by my future or my past, I start to feel a weight lifted and I start to feel a feeling that's a little bit like freedom.

And it's easy enough to say that it's therapeutic for us to live in the present, right? But what does that really mean? We can't really live in a way that we are impulsive and not taking account of all of our obligations and responsibilities, which we all have. And so, I think of living in the present, like, Jackie, if you could go to the next slide, I imagine living in the present as this



photograph, right? That we're all kind of on this high wire balancing act. We're in this magnificent canyon, right, but we need to focus on putting more one foot in front of the other, on the very next move and keeping our balance. If we get too distracted by the future, by the past, we'll fall, there's death and there's risk all around us. And it's very real, but there's also, you know, magnificent beauty all around us, like in that canyon.

And so, the goal I think of living in the present is maximizing our ability to focus on putting one foot in front of the other while also being able to enjoy the beauty all around us. And one way to do that is to plan for the future, right. Because getting our legal affairs and our financial affairs in order now certainly gives us some head space to feel a little bit more at peace in our moment now. So, I'm here to talk about the conversation that nobody wants to have, the fun killer of the documents that you get together to prepare for your death or your incapacitation, which is not as fun as the life hacks we were just talking about. But I talk about these two categories called life and money, planning categories, Jackie, if you don't mind moving the slide forward, all of the things that go into your planning documents, I call them, they're designed to do two things, right?

They are designed to help your loved ones or your legal representative in the event of your death or incapacitation to ease their burden. And they're also designed to give you a little bit of control over your stuff and your family when that happens. Many of us don't like to think about this. Some of us know that we need to put these things in order, but we somehow put that idea on a shelf and we just like, look at it every once in a while, but we never take it down off the shelf. I'm sure that many of you are way ahead of me on this and you have all your things together. I learned as I was preparing for this presentation that I actually have none of this together yet. So, my shelf certainly, I have my, all my stuff in a box on a shelf right now in my head, and I'm gonna take it down right after this presentation.

But what I've learned in looking at things that we need to prepare for, for our death or incapacitation, and this goes for anybody, whether without Parkinson's right, is that when you talk about what I call the money documents, those are things that number one, that a lawyer can get together for you. I am a lawyer, but I'm not a trust and estates lawyer. And I do have to say, because I have an active license that I have these weird advertising rules that I have to pay attention to, and I'm not allowed to give legal advice. And so, I have to make a statement whenever I talk about anything remotely legal, this is not the giving of legal advice, which is gonna be obvious anyway, when, cause I don't have any legal advice to give, but so, if you wanna move to the next slide, Jackie. When it comes to the money documents, we're talking about the life estate, I'm sorry, the estate planning documents that everyone needs, which is a will, which of course provides instructions, a trust which takes care of your property, powers of attorney, which you should have two of them, one for your financial life and one for your healthcare life.

Those are basically, you know, where you delegate or designated person who can make decisions for you in those areas of your life, according to your instructions. And that person will have access to your documents where otherwise access would be prohibited or not given in conjunction with those powers of attorney, you're going to have to have a HIPAA medical release permission form, which, you know, gives your designated representative access to your medical records that HIPAA would otherwise prohibit. Those are the things that I think it's helpful to have a lawyer draft for you because it's so complicated and there are so many different rules that you have to follow to the letter. You have to dot the I and cross the T or none of them will be effective and they're vastly different from state to state and they change all the time. I would never wanna do any of those documents, the DIY fashion, for that reason, but some of the DIY programs out there are helpful to have you start thinking about some of this stuff.

The last thing of course, which is what a lawyer can also help you get together is the advance directives. Those are the, you know, the medical directives mostly, but they can be other kinds of directives too, where you have to sort of imagine these horrific scenarios that are gonna happen to you and then decide what kind of life life-saving or life-sustaining treatment that you want. And that's really the most fun part of all, a lot of stuff that needs to be done. But the other part of the money stuff is not what a lawyer needs to help you with, but just things that you need to gather of your own financial life in order to help you, help your family members, help your representatives work with all of these documents, right? So, someone needs to know what your insurance policy says, who the contact person is for all of those documents.

Someone needs to know where your deeds are, or your leases, or any other documentation with regard to any of your assets, all of your banking accounts. And they need to have the actual official documents in order for all of this to work. And getting all that together is, you know, something that takes a little bit of time. So, you do have to plan for this stuff. As Marty said in the last presentation, right? Planning is everything. But on the other side of things, which I call the life side, this has two parts too. The first part is, again, all your identifying documents, your marriage, your divorce, your adoption, your custody documents, all the things that someone would need to take these legal steps for you. Also, someone needs to know all your passwords, where to find all your passwords, how to get into your, how to get into all these accounts, right?

Your emergency contacts. And the last set of documents is what is referred to as personal instructions or final instructions. And those are things that you wanna pass down to your family members and your representatives about what your values are and what is meaningful to you. The more you can write down your values and what you believe in and what you hope for, the more all these other legal documents will have significance. Sometimes the legal documents like the advance directives are not followed because of the circumstance. Those things are happening really fast. The particular doctor that you are, that is at your side, doesn't have access to these documents at the time that decisions need to be made. And so, they're not

infallible which is why it's important to have as many different touches, right? As many different places and as many different people who will be surrounding you to know what your wishes are.

And I just saw in the chat, there's a ton of good book and all this stuff, and I put some resources in the handout, but there's a workbook on Amazon that I found yesterday called I'm dead now what, which someone just posted in the chat too. It's got 8,000 5-star reviews. So, there are so many different, you know, things that are gonna help you walk through all these very difficult decisions to make. But I do think that what's more important than talking about all these things is to actually do them, actually get them all together. Right. And on the next slide, Jackie, if you don't mind, there are some ways to do it, that you can inject a little bit of fun into getting your documents together.

I heard Tom Hanks the other day, give an interview. He has his annual colonoscopy. He schedules it with a bunch of his friends and they get to the night before and that they have like a colonoscopy prep party where they all sit around and they drink the stuff. Right. And it just makes it more fun. And that's, you know, that's something that you can consider to set up a system or some accountability for you to get all the stuff together. It does take time, right? And so, you can have something that's been referred to as a document dossier party, where you just invite friends over and you work together to talk through some of these really hard conversations, but you get it done. You know, you get your documents, at least partly in order, you can also do that just through you know, a regular support group meeting say, hey, for the next eight weeks, let's work on these eight steps to get all of our documents and affairs together.

Or you can do it yourself, just, you know, set aside an amount of time, a big chunk of time, you know, pretend like you're going to a retreat, make your own little retreat and have nobody else bother you for what, a day, two days, maybe three days to get this all done. It's obviously it's very important for not just you, but for your family and your loved ones, or you can, you know, you can, if you're good at self-accountability you can create a schedule and a calendar for you to get all these things together and give yourself a reward at the end, whether that's the chocolate ice cream or you know, the walk or the bike on the beach, things like that. What's really, really important about all this stuff is that it's not all in your head, that people know where the documents are, where your final instructions are, and they know how to access them when they need to. And for that, there are a lot of resources on Amazon. You can just have a workbook and have everything all in one place. There's also a really good website called five wishes, which I'm sure that some of you, or many of you are aware of and that's five wishes.org. It is a website that helps you go through all the different, difficult questions that in are involved when you're doing advance medical directives.



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