



How to Start and Run a Parkinson's Support Group

Davis Phinney Foundation

Note: This is not a flawless, word-for-word transcription, but it's close.

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

Okay. Hello and welcome everybody. My name is Melani Dizon. I'm the Director of Education and Content at the Davis Phinney Foundation. And today I am here with a whole slew of ambassadors. We are feeling like the Brady Bunch Clan today. And these we're going to talk about support groups. We have a lot of questions from people saying, I don't belong to a support group. I'm not, I haven't heard anything about a support group in my area who have questions about starting one and wants to know how to make them successful. And so, I have gathered this very experienced group of people to talk about just that. So, I'm going to call on each of you as I see you on my screen. If you can just tell us who you are how long you've been an ambassador, and your experience you know, how long you've been doing support groups, and what kind that would be great. And then we'll get into some of the deeper questions. So, Patty Burnett, you're the first person on my screen.

Patty Burnett (Ambassador, Davis Phinney Foundation):

As you said, I'm Pat Burnett. And PS 2013, I apologize because we're driving from a doctor's appointment now. But let's see. When I was diagnosed, I knew that I needed to be part of a support group, and so I found somebody who already had Parkinson's, and sure enough, she had just started a support group. So, we helped I helped her some, and then eventually when she got tired of it, three of us took over. And that's our status right now. It's been wonderful.

Melani Dizon:

Oh, great. Thank you. Carol?

Carol Clupny (Ambassador, Davis Phinney Foundation):

Hi, I'm Carol Clupny and I live in Hermiston, Oregon. When I moved here to get my first job out of college, there were 7,000 people in this community. And since then, it's grown. But I was diagnosed in 2008 and in about 2010, I realized that I was pretty lonely. So, I asked the physical therapist, and I said, we need to start a support group. And she goes, you will start it, Carol. So, my husband and I started the support group here, and we've gone on since then. And we've been the facilitators for all these years. Wow. That's great. Thank you. Carol. Stan?

Stan Livingston (Ambassador, Davis Phinney Foundation):



Yeah. I'm Stan Livingston. I'm from Madison, Wisconsin. I've been diagnosed for about eight years with Parkinson's, and I facilitate two support groups with help from others. One we do after a Rock Steady Boxing class, and then another one in a different community we set up to that meets actually after a different exercise class. So that's kind of, that's been going on for three or four years.

Melani Dizon:

Nice. Awesome. Greg?

Greg Richard (Ambassador, Davis Phinney Foundation):

I'm Greg Richard. I live in Panama City Beach. I was diagnosed on April 26th, 2011. So that's almost 12 years ago to the day. And tomorrow I have DBS surgery, so April 26th is turning into my second birthday.

Melani Dizon:

Oh, wow. That is,

Greg Richard:

So, I kind of look at it. I've had a lot of experience with setting up support groups. I set two up in Colorado, and then when we moved here, couldn't find one. So started another one here. It's called 30 85 Thrive 30 and 85 are simply the longitude and latitude of Panama City Beach and Thrive is what we intend to do despite having Parkinson's. So that's in a nutshell my story. I would also add that I think it's pretty obvious that humans are pack animals. We like being in a pack. We like belonging to a group. And there's, especially when you have a disease like Parkinson's, there's a huge socialization need that's met with that.

Melani Dizon:

Great. Thank you. Joe.

Joe O'Connor (Ambassador, Davis Phinney Foundation):

Yeah. Hi, I'm Joe O'Connor from Sterling Massachusetts. Kind of a funny story, about how my support group came about. I was going to another support group, and I had gone up to the senior center where I was working for them in different capacities. And I said it'd be really great if we brought these people up. So, I went down and talked to people that led the support group, and they said, why don't you do it? And then I was in seeing my motion specialist who, and she said, you know, there's really need for a support group in Northern Ward County. And I said, Hmm. So, I went back to the senior center person, and I said, well, like good news, like bad news. The good news is we can get a support group going here. The bad news is it's me.



But I've been doing the support group now as long as I've been an ambassador. Well, a little bit, a little bit longer than being an ambassador. I started in my support group in March of 2018. We went right through the pandemic together. We, because and I agree with the comment, comment about socialization because it was difficult for people to get with Parkinson's to have socialization during the pandemic. We went to a once-a-week schedule, and when we just got together and play games and talk about what was happening. But I think you know, I just want to say to people that are thinking about leading a support group, do it. It is an incredibly beautiful experience. I mean, it's the so wonderful that you can make that much of a change in somebody's life with such a little, little bit of effort on your part. I mean, go ahead and do it. Don't be afraid of it. If you're afraid of it, contact the foundation. They'll put you in touch with one of us and we'll help you to get over it.

Melani Dizon:

Yeah. Oh, thanks, Joe. That is great. Michelle.

Michelle Lane (Ambassador, Davis Phinney Foundation):

Hi. Excuse me. I'm Michelle Lane. I was diagnosed in the year 2000, so it's easy to figure out. 23 years ago, I have been an ambassador for five years now with the Davis Foundation. And it was back in 2003. I met two other gentlemen that were two other gentlemen that were diagnosed around the same time as me. And there were no support groups, that one little, tiny one that had a few older people. So, we started the Young Onset group, and it became welcoming to everyone and grew very large until COVID hit and we couldn't have it at our location anymore. So, we just started our second group now.

Melani Dizon:

Oh, great. Thank you. Patty.

Patty Wargo (Ambassador, Davis Phinney Foundation):

Hi, I'm Pat Wargo. I'm from the downtown Pennsylvania area, a place called Center Valley. I'm new to Lehigh County. So, I've, I'm doing a lot of seeking out to see what's, what's available to people. There are support groups available in the area, but I also belong to the Rock Steady Boxing Group. A club, well class that classes that ask for a support group. And so, I started one with them for women, women with Parkinson's, and also for Care partners. So, I have two groups going once a month. My background is in working in schools and with schools too, and one of the things that I did with them was to teach them how to do groups and how to identify kids, how to work with kid people, not just kids. So, there are basic group facilitation skills that I've had for many years, including my professional life, probably about 30 or 40 years now that I've been doing groups. The, my Parkinson's started in two, well, I was diagnosed in 2004. Probably started a lot sooner than that. And I had DBS surgery about seven years ago, and



that's been wonderful. Good luck, Greg. Greg, I hope your experience is as good as mine was. is. And I feel great. I feel like giving back as an ambassador for two years now. I give back to my own, my Parkinson's community, and it's very rewarding. I encourage anybody to get involved with doing things like this.

Melani Dizon:

Yeah. Thank you, Pat. Doug.

Doug Reid (Ambassador, Davis Phinney Foundation):

Hi everyone. I'm Doug Reid. I'm in Lafayette, Colorado, just outside of Boulder, just outside of Louisville, where the foundation headquarters are headquartered. I've been an ambassador for just over a year now. And oh, I was diagnosed in 2010 when I was 36. So, I attend a general Parkinson's support group meeting that meets monthly. I regularly attend a young onset meeting support group that meets monthly. And I co-lead a DBS support group that meets monthly via Zoom.

Melani Dizon:

Great. Okay. Well, we have so much experience on this panel. I'm so appreciative. Just by a show of hands, how many of you for those support groups that you lead, and how many of them are solely in person? Okay. All right. So about 50%. How many are hybrid? Sometimes you meet in person, sometimes you meet. Okay. All right.

Joe O'Connor:

We also sometimes meet at the same time, virtual and live.

Melani Dizon:

Okay. Great. Yeah, that's good to know. How many people run a support group that regularly over 20 people attend? Okay. Okay, great. So, Michelle, you've got a big group, obviously, that one big group you've had to move, or you've split into another group, is that right?

Michelle Lane:

Actually, split into another group, then Covid hit, and we lost the facilities. Okay. Daytime, we had daytime on a nighttime group.

Melani Dizon:

Okay.



Michelle Lane:

One was at a hospital; one was at assisted living. So, we couldn't go to either one.

Melani Dizon:

Great. Finally

Michelle Lane:

They started back.

Melani Dizon:

Okay. So, I'd love to some of these are going to be, you know, pretty quick. We've got people that have a ton of questions. But so, you, let's just, let's kind of walk people through it. So, you decide, hey, I have to run a support group. There's a need. You find a need and you decide to do it. What are some of the ways, the most effective ways that you've used to recruit people? Joe?

Joe O'Connor:

A big thing that people tend to overlook is houses of worship. Because they don't tend to take things down.

Melani Dizon:

Like flyers,

Joe O'Connor:

You know, like, you know announcements. My church has a Lenin flyer from two years ago up. Okay. Do you know what I'm saying? But it's an advantage for you. You don't have to worry about the fact that you have to go and refresh it. Also, people look in the back of those kind of places and they say, oh, there's something. And they feel more comfortable finding it in a location like that, rather than like, on the side of a store. They don't want somebody looking at over their shoulder and going, oh, you have Parkinson's. Do you know? Yeah. It that, that's one of the, one of the other ways. The other way another good way, of course, is senior centers themselves, although they do have a habit of taking things down. I, there's a thing in about a less than a mile from me. It is not the one I use, because the one I use is just over a mile from me. And they keep taking down my thing and I go, just leave it up. I mean, you know if people need it, they'll use it. And they go, well, no, we, why make sure we get it up to date. And I'm like, it doesn't change. The last thing I'd like to say is another good location is libraries. Libraries are also very, very good. And they're also very good about not taking things down again.



Melani Dizon:

Great. Thank you, Michelle. And then Carol

Michelle Lane:

We take the flyers and of course, put them in the physician for the neurologist offices. We also create a welcome packet that said, sometimes with the, any victory counts manual in the little bag, doctors give it to the new limited newly diagnosed, excuse me.

Melani Dizon:

Yeah, that's a good little, little swag bag. Carol.

Carol Clupny:

We knew just about one or two people with Parkinson's when we started our group. So, we got going with flyers all over the community in the laundromats, on the bulletin board at the supermarket, just everywhere. As well as to dropping them off at any HE health, all Allied Health Alliance, whatever, like speech people and PTs and all those people that someone with Parkinson's might see. We also did social media. We put an article in the newspaper, and we tried to cover every/ Oh, my husband went on the radio. Yeah, of course, he did. I love that. Yeah. Hat Burnett.

Patty Burnett:

Yeah. I, as I was thinking about this, I realized that I wish that we had a website and I'm sure that there's somebody in our group that probably is pretty acquainted with starting a website. And I'd be curious to know with you guys do any of you have websites.

Melani Dizon:

Oh, not from me, Greg.

Greg Richard:

Yes. To answer kind of both questions coffee houses are another great source of things and sort gyms. We found that we get a lot of activity out of gyms. Patty, to answer your question yes, I think it's always critical. It is not me. I'm not a technologically oriented person, but I found a person that was willing to create a website and put all, all the, you know, structure, who we are, what we're trying to do, what our vision is, what our mission is, what our objectives, what do we talk about and put all that onto a website for the people that are technologically savvy in doing that. And that's my middle daughter. And that gives me a fathership override.



Melani Dizon:

I love it.

Patty Wargo:

Is that the,

Greg Richard:

Actually, it's almost the opposite. I should have said because she comes up, you know, Dad, you just don't understand, and this is what people want. You're like, oh, okay. You know, I would send out the exact same message 17 times and she goes, no, you know, dad, there's a thing called groups, you know, and you're like, oh, really?

Melani Dizon:

Right. efficient. So, when you were recruiting, how did you, like, what were some of the things you did to make sure you got the right people? Or were you just, hey, whoever is Hess, Parkinson's is the right person? Like, did you ever, did anybody have any, yeah. Okay. We're all on board for that. Does anybody have anything different? There just come no matter what. Okay. Patty and then Doug.

Patty Wargo:

Well, when we started our, group at RSB we wanted the women to have a place to go with there, with their issues. They're different in some of them. And so, we advertise as women with Parkinson's and that there were like 19 women that showed up the first time. Wow. That dwindled down quite a bit. And now we have about six people that show up you know, on a regular basis, not the same sex all the time, but around six at, at each session. So that's not me.

Melani Dizon:

That's great, Doug.

Doug Reid:

Well, our group is for people who have DBS or for people that are considering DBS. So, it's kind of unique in that facet. But we do have at least one gentleman who was interested in DBS and decided he didn't want it, but still wanted to be part of the group. Because we do talk about all things Parkinson's in addition to just DBS-related issues.

Melani Dizon:



Yeah. Great. What would, what would you say are some of the challenges or surprises that you've had to deal with negotiate as a group leader, Joe, and then Patty?

Joe O'Connor:

Yeah. I think the biggest one is that you, sometimes people will feel very comfortable and will want to have a, what we call a pity party. And you have to allow that to happen because it's real, but you can't let it swallow up the entire meaning because all the other people will feel like they didn't get a chance to express themselves. So, it's a kind of a tightrope walk that I've experienced a number of people in the group that have had trouble and stuff like that, and they needed to but also needed to not, you know, completely monopolize the meaning.

Melani Dizon:

What are some of the strategies you used when you when that comes up?

Joe O'Connor:

I'm a former Toastmaster. So, what I do is I believe in a clock. I'm not saying that I have a clock that I show them or anything like that, but I believe that you know, people, if we have an hour and a half meeting, which is the length of my meeting and we've got, you know, 20 people, then I believe that we have to limit people to a certain amount of time each time. Like maybe five minutes. On the other hand, if you have like a seven-person meeting and I've had seven and smaller, in fact, then you have more time. And if people want to talk longer, that's fine too, you know?

Melani Dizon:

Yeah. okay. Dan and Dan Patty, and then Stan.

Patty Burnett:

So, I think now, I, oh, go ahead. I find that we have a tendency to, we want to talk about living right? Even though there is death that goes on. And so we are, we're really active and we concentrate on living better, like is our philosophy with Davis Spinney. But for some reason it just hit me, hit me really hard the first time that we lost somebody from our group. And so, I guess a bit of surprise about people dying, even though that should not be the case. And so, we needed to figure out a strategy how to deal with that in a proper way.

Melani Dizon:

. what were some of the things that you did together to process that?

Patty Burnett:



Well, we tried, tried to do a good job of attending memorial services with each other so that we had closure. We, and we talked about it, you know, we talked about it as a group just so that people could feel like they were able to grieve in a good way.

Melani Dizon:

Yeah. Great. Stan?

Stan Livingston:

Well, when Joe was talking, it made me think of trying to find a balance between being living well, like the Davis Phinney recommends, but also recognizing that Parkinson's is a very difficult disease for many people. It's progressive and it's, there's a lot of, as we discussed, many difficult aspects of it. So, I think in a good support group, we need to find the balance between finding the good things about the positives and also not ignoring the negatives or recognizing the negatives.

Melani Dizon:

Yeah. Greg.

Greg Richard:

Yeah, I was going to say, in regard to both of these topics, one of the things that we work on, or early in establishing a support group is what are the topics that are near and dear to these people? What do they want to talk about? And death is certainly one of those issues. We, about three months ago, experienced the first passing of a person in our Florida group. We have had social workers come in and talk to our group. An organization that I'm part of called Jack's Hope, that is basically a loose affiliation of about 17 support groups in northern Florida. We're in the process of interviewing and hiring a part-time social worker just to handle those issues. We had an issue one time, a divorce, a new, you know, a newly diagnosed gentleman, and his wife came, they came to one meeting, didn't show up for two more meetings.

Greg Richard:

I called him back just to check in and he said his wife said, that's it. I'm not going through this and checked out. You know, those are the kind of things that they're not going to happen every time, but you need to be, you know, sort of prepared. And that's where resources, like every victory counts and, you know, things that national and regional organizations have the size and the capacity to help you with. So, you know, you've had to be in a position to talk about that. We've incorporated a, I have a couple of speakers and I've developed a list of speakers on all the different topics because I think that's critical for a new support group getting started, who

do, who do we get to talk about? And you know, Wayne Gilbert, he's a creative writer. And we've done some poetry sessions with him, both live and on Zoom.

And we've done some therapeutic art after Jack, the gentleman that passed away he loved art, and he loved painting. And so, we all went out and bought some easels and we had a jack painting party instead of a pity party. And everybody drew, you know, what made sense to them in the world of Parkinson's. So, I think it, it's, you know, fair to assume that anything that's going to happen to a normal person is going to happen to a group with Parkinson's. It's just being prepared and reaching out when you if you know, when you get stuck with you know when I called the guy and he goes, my wife divorced me. You're like, you know, let's see, what experience do I have with that? A, no B, none, C none. Yeah. Start, start dancing, Greg. And, but when you get through it and the more resources that you can show people and help them do that, I think the better they feel about being involved in a group that's there to help them in their time of need.

Melani Dizon:

Yeah. Pat, I have a question for you. You know, as this, you know, being part of your actual profession and there are a lot of people that will tell me they feel ill-equipped. What if, what if some, what if somebody brings up an issue that's, you know, really a big issue and they don't know how to deal with it? What are, what're some things that you can offer people for handling things like that at the moment?

Patty Wargo:

Well, I think first of all, all of you are good listeners, and that's the primary, a primary requirement. I think for, as a group facilitator, I also think it sign video. It's okay to say that you don't know, or you don't have the answer. You know, I'll find out would the group, does anybody else in the group have this experience so that, so it's not just on you. Especially if you've got Parkinson's too. You know, you're going to have emotions and feelings about the different topics that you cover in the group. And it's important not to think that you have to have all the information. If you keep the EVC book next to you know, it's always good to refer to, say, well, let's look that up and see what they, see what this has to say.

I think that when I did groups, I, oh, I did mostly kids groups, but I did do a lot of adult groups too, now that I think about earlier in my career. The types of things that people come out with sometimes are very surprising and scary to you yourself and can hit a chord with you that twangs, you know, that doesn't feel so good. And I think that it's important to lean on the other people in the group to help you through that, whatever that issue might be. And be very okay with it, I'll come back to you with information about that. I'll give you a call this week and let you know what I find out so that you're not feeling like you have to remedy the world's ills with just you know that you don't have all the answers. And so, keep that in mind. You're still a good leader, a good facilitator. You don't have to have all the answers.



Melani Dizon:

Right. Thanks. Doug. And then Stan.

Doug Reid:

I was just going to say, Patty brings up a good point that everyone with Parkinson's is different. sometimes you may not have experienced the same things that other people have experienced. Right. But if you know others in the group may have, or in my situation, I'll ask the group, has anyone else experienced this?

Melani Dizon:

That's great. So, and-

Patty Wargo:

It's good. I'm sorry. Oh, go ahead.

Melani Dizon:

Yeah, go ahead, Pat.

Patty Wargo:

I, that's exactly right. Asking other people, especially in this, doing this type of group where we can experience losses, we can experience people going through DBS and not having a good experience people who have had a wonderful experience, and make sure that you allow time for that people to process those things. I never go into a group either, but saying, this is the agenda that I have for today. You know, I'm, I have ideas that I have, things that I think the group's ready to talk about, but I don't push on my agenda on them. You know that the group has to, you know, what's going on this week? How's everybody doing? And trying to do like a game or an icebreaker at the beginning that kind of just lets people loosen up and get, get, feel welcome, especially if you have new people. That's important too. So

Melani Dizon:

Thanks. We'll often do. Good. Sweet, then, Joe.

Stan Livingston:

Yeah, so I would just build on those really good ideas. I think that you know, one thing I try to do in our groups is to develop a sense of group identity. This is our group, and we can make it what we want it to be, and we can support each other. And we all, if we work together, we can

all have the answers together. And the other thing I think a good facilitator can do is to identify the problem. You know, this, we're feeling sad about this, we're feeling angry. you know, this is scary. You know, and just sort of help the group understands to some degree what, what's going on, what's being discussed. And then asking the group for solutions. Because you know, we're all in it together. We can all learn from each other. I learn more from them and when I go then they might learn from me. So. it's really helpful that way.

Joe O'Connor:

Yes. I think of it as a continuous brainstorming activity going on. I just want to say something, Patty, you mentioned games. Games are really a good idea. I always pack at least two games with me when I go to my group meetings. Just what I mean, even if you just like, some like trail pursuit and you come up with some sort of absurd question, people get a laugh, they start to interact and, and they feel more comfortable with each other. And it's also good cognitive training. So, it's, it's a two-for-one, you know. So, I just think one of the things I always do is I always pack a couple of games with me. Not anything sophisticated, nothing hard. In fact, online games are really good in that respect because you don't have to carry more than your phone, you know?

But though those are really kind of helpful. They, like you were saying, breaking the ice is a very important thing especially when you have, and I don't know if other people are experiencing this, but I've had sort of a turnover. We lost some people through the covid and stuff like that, but now people are coming back and I'm getting newer and newer people and they're feeling less and less comfortable because of many, many reasons. But what you want to do is you want to make those people feel like, okay, this is a good place for you to be. You can be calm and health help and healthy, and I'll shut up.

Melani Dizon:

Pat, you have something more about that. Yeah.

Patty Wargo:

One of the things that you can do as a facilitator, and I find this really people more comfortable, is to break it down into small groups. I did a presentation for our PD steps program last month, and the guy who organizes it as a physical therapist, and he was really surprised that I did this. And it worked really well. I said, yeah, well, it's worked for me for a long time where I asked a question, I gave the groups, I broke them into small, small groups and gave them a question to talk about. And was there anything, you know, really hard or that they had to get, have a lot of information about? I can't remember what the question was now, but I give them a question and have them work on it. And then I floated around from table to table and just make sure that everybody was getting a chance to participate.

If there's anything that that is coming up that I noticed, somebody's looking like they're having trouble with it, you know, with the discussion that I might bring, bring a comment to the table myself but making sure that they know that I'm listening and I'm circulating as well as the group is becoming more comfortable with each other because they're, they're talking me with somebody they hadn't talked to before. Because, you know, they come in and go out and, you know, they stay for the program and then they leave. And so, it gives them time, it breaks down the defenses, it gives them time to feel comfortable with each other. Because asking people questions in a large group, especially Michelle, your group was really large. You know, to do that successfully, it is difficult. Unless, unless you have some tricks up your sleeve, you know? Right. So,

Melani Dizon:

Thanks. Michelle?

Michelle Lane:

I have a trick. Well, we've done it a few times. We do a few times a year take the caregiver care partners and put them in another room. put the Patients together so the Patients can discuss things, you know, without the care partners there. And the care partners do the same. We can't get the care partners out of the meeting. They're laughing and enjoying each other.

Patty Wargo:

That's right. Yeah. The times we've done that, it's the same thing.

Melani Dizon:

How many people here have both the person with Parkinson's and care partners in the group? In their groups? Yeah. Everybody. Okay. Yeah. Almost everybody. Yeah. Great. Greg, did you have something? Yeah,

Greg Richard:

Yeah. I've put together a deal. I think for me, you have to answer the four basic questions of what's going to attract someone to a support group. Number one, what's Parkinson's? What is it, you know, what are the questions you ask when you first hear you have Parkinson's? What is it? Why me? Why did I get it? What's going to happen to me now? And who can help? And then we follow, I have a format that, you know, it says what we're going to talk about. We're going to talk about community hope, exercise, education, research, and self-advocacy. And so that acronym is cheers. And so, we just came up with an acronym. So, when people say, well, what do you do at your support group? You know, we say we're going to, there's going to be



information and a speaker on any one of those arenas so that people kind of have a sense of what to expect and they don't come into it blindfolded or dumbfounded in doing that.

And then the other, the last thing I'll mention, I've heard this from a couple of people now they don't like the comment, oh, I would never join a support group. You know, they seem to have a negative connotation to the support group. That's why we named ours 30 85. Thrive doesn't say anything about Parkinson's, doesn't say anything about you know, support group. But our slogan is, we're not here to find a medical cure. We're here to help you find your cure. And that seems to resonate with a lot of people that that's what they want to hear. Everybody's Parkinson's is different. there's no one, you know, a map that's going to solve all the problems. And that's, we're just a collective group of people trying to figure it out together.

Melani Dizon:

Yeah. Sounds great, Patty.

Patty Burnett:

Yeah, that is really good stuff, Greg. You know, as I've been thinking about the questions that Mel told us, I realized that we so much as leaders, we have a three-person leadership and we so much need to be positively living the way we say that things are important. You know, we need to be doing the exercise and they need to, like, one guy came up to be at our last meeting, he said, I just, I want to be the way that you are as you know, when I'm 10 years down the road. And so, it's so important for us not to just be telling people what to do, but actually be living it out so that they see it happening in our lives. Walk, walk the talk,

Melani Dizon:

You know?

Joe O'Connor:

Yeah. Yeah.

Melani Dizon:

Exactly. Yeah. Does anybody have something similar to Greg in terms of, you know, that's clear? This is what we do, this is what we talk about. Does anybody have any, maybe call them, like rules of engagement that you share with new members? Or anything like that? I feel like whenever I did group counseling, we always did, you know, sort of rules of engagement. But it's sometimes it's different, you know, with an open group than with closed groups. So, does anybody have any thoughts on that, Patty?

Patty Burnett:



We don't have anything written like that, Mel, but what we do is hopefully we are again being polite, you know, allowing people to talk so that nobody is dominating the conversation. Just making sure that we're really kind to each other, we're loving each other, encouraging each other you know, just be, we're like family to each other. And especially in cases, which it's so many surprises me, you know, was it Greg who said that he had a couple that got a divorce when that was in their support group. If we can encourage each other and be family to each other, that's, that's huge.

Melani Dizon:

Yeah. Thanks, Carol. And then Joe, and then Michelle, we talk a little bit about confidentiality and how, you know, if you don't want to hear somebody talking about you at the grocery store, it's a good idea. Just kind of keep this under your hat. It's, it belongs in our group. Yeah. That's great. Joe.

Joe O'Connor:

I like the family concept. Been through a lot of things with some of the people in the support group. And I told them right straight out. I said I love you guys. I said you're my second family. I mean, and they looked at me like I was, you know, I said, no, I really mean, I mean, we've been through so much together. I mean, we were on in a group meeting when the capitol was, you know, the January 6th was the Wednesday, so we were in a group meeting and I remember us all just going, not that we were trying to be religious or anything like that, we all just said we wanted to say a prayer for the country right at that moment because that's how we felt. And I think that that's a thing, I think Patty's right about not having a list written down but understanding it and absolutely. I always tell people you know, whatever you say to me is in confidential is confidential. And but if you want to say stuff about me, me

Melani Dizon:

Michelle?

Michelle Lane:

Yes. Actually, we have a social hour or half hour, either before the reading, and then it usually, it'll turn into after the reading again, so the people can gather and speak and get to know one another.

Melani Dizon:

Yep. Oh yeah. That's nice. That's nice. Patty, were you going to say something, Pat? Oh, yeah.

Patty Wargo:

I think that basically what we're talking about is creating a safe space for the people that are in the group. And you're all doing it very well, and you don't have to have a long list of written down rules. But confidentiality is really important to let people know that we need to keep what people say stay stays in here. Or if you want to talk about it with that person outside, talk about it with that person when nobody else is around. So, creating the safe spaces and that family feeling is marvelous. That's, that's just a really good way to put it. You know that you're there for them through thick and thin, you know, it's a little important, but confidentiality is probably the most important thing in creating that safe space.

Melani Dizon:

Right, Greg?

Greg Richard:

I found a cute little way to do it. My daughter who is a teacher, showed me this. It's a little, it's a little placard and it's saying, you know, everything you need to know how to live your life correctly. You learned in kindergarten, kindergarten, kindergarten,

Patty Wargo:

Yeah.

Greg Richard:

Kindergarten. And so, kindergarten rules apply here. And that I put that out at the beginning, and I've never had an issue.

Melani Dizon:

Right. That's great. Has there anybody who's ever had anything that was, you know, a real challenge and you know, beyond the just normal things of a day-to-day, but it was a really difficult challenge? And is there anything that you could share about how you navigated it? Carol and then Joe.

Carol Clupny:

At one meeting, the husband and wife came to, the wife was in a wheelchair. She had Parkinson's and her husband with her care partner, and they came in just this god-awful fight. They were yelling and I thought he was going to hit her. The physical therapist who started the group with us at that time was there, and, we were at the hospital, so she went out to find some help. And she got those people out of, our room somehow into the social worker's office. And so that was a good place.

And that the social worker helped them work through some things. But I ended up having them go, helping them go to the assisted living and checking out, you know, separate living con situations and such. And it was really a challenge for me to, you know, like, want to protect the woman and want to listen to the man and, you know, it was just quite an experience. Yeah. Oh yeah. You were in the right location for that to happen. Yeah. Yeah. Better than Denny's in the bar. We have been there for a little bit. Private library room somewhere. Yeah. We meet in the bowling alley now. Oh, Joe. And then Pat.

Joe O'Connor:

Yeah. So, we had a situation where we had a guy come on onto the group meeting, and he was young onset, and he was pretty much suicidal. Mm. And I recognized that everything that was being said to him was upsetting him further and further and further. So, I'm going to use Joe was his name. I said, Joe, I said, you know, if you want to talk about this, let's talk about it offline. And I told him, I said, you know, he was like, I don't, I don't, I'm very depressed and all this kind of stuff. I said, well, I would suggest you do what I did. And I said, go, go. You know, go see a psychiatrist. Go see a professional. Well, to make a long story short I just armed today, he's had d p s surgery he's doing really great. He recognized me more than I recognized him because I hadn't seen it for like 10 years. Oh. I mean like three years. So, I mean, it was, you know but the whole thing about it is it goes to what, what, what Patty was saying in a different way. And that is realizing you can't handle everything yourself. Some of these things are, are beyond, our capabilities, and for the sake of the people we need to involve other, other people. And Carol, your thing sounds scary.

Carol Clupny:

Yeah, it is.

Joe O'Connor:

I imagine it was.

Melani Dizon:

Yeah, Pat.

Patty Wargo:

Well, I'm trying to remember now what I was going to say. Sorry. Parkinson's moment, you know, not working well. I think that part of what we need to do as, as facilitators is to have a safe place for ourselves to go to somebody to talk. Because those two situations that you two just shared are serious enough that they have an impact on you emotionally. You know, so having somebody either from the group, preferably from the group or co-facilitator or the

social worker involved or the physical therapist, somebody you could sit down with after the group of the process with them what had occurred or has occurred so that you're not left hanging, you know? Yeah. And going home and carrying those emotions and feelings home.

Melani Dizon:

I mean, think about, yeah, I think about as professional therapists, I always had a super, I always had somebody, right? Yeah. Really tough situation. And so, and then I was trained to do that for a job. Yeah. So, yeah. You know, stepping into these things, it's a lot. And yeah, I think it's really great. How many of you have co-facilitators that co-facilitate? Not right now. A couple of you. Of you. Yeah. Yeah. That's tough. Okay. Gosh, we are, I mean, I feel like we are, I could just keep talking about this. This is so interesting. What have, let's talk about what have you learned from running a support group in terms of your own experience with Parkinson's? What, what have you learned? Yeah, Patty,

Patty Burnett:

I am finding that by helping other people, it's probably the best possible thing. You know, the most valuable thing that I can do for my own health. So, it makes me feel like I have a purpose. I'm needed. And that's just been, that's been huge for me.

Melani Dizon:

Yeah. Feeling

Joe O'Connor:

Ditto. I mean, that's ditto.

Melani Dizon:

I said that. Ditto.

Joe O'Connor:

Ditto. Ditto.

Melani Dizon:

Yeah. Anything else?

Stan Livingston:

Well, it's just being part of a community, you know, and for me, it's being part of the community. We all, I think with Parkinson's, we, a lot of us tend to be more isolated and just



getting out and being with other people more and sharing I've, I've learned a lot about Parkinson's, just sort of preparing for groups and learning about topics, watching webinars, and sort of try to educate myself. It helps me to deal with the disease.

Melani Dizon:

Yeah. We're not they're not alone. You're not alone. They're not alone.

Patty Burnett:

Like you.

Doug Reid:

Yeah. We've all heard the expression, if you've met one person with Parkinson's, you've met one person with Parkinson's. Yeah. But it's really hit home to me how different each of us is and how much we share experiences too.

Joe O'Connor:

Yeah.

Melani Dizon:

Some final last pieces of advice for people who are watching this and kind of went from, oh gosh, I want to start a script group. I'm starting a support group. This sounds amazing. what is the sort of nugget that you'd like to share with them? Hmm. Patty and then Joe.

Patty Burnett:

I would say that to somehow get across to everybody that's part of the group, that it's not my group. It's their group. And give, for instance, one guy said he really hoped that we would have a session that talked about research where, you know, cutting-edge things that are happening within the Parkinson's medical community. And I said, okay, then why don't you lead that group? And so, he's doing the research about research, and I feel like even though he is just a pretty new member to our group, he is taking leadership, a leadership position. So, he's, it's his own group. He's taking ownership and that is really important, I think.

Melani Dizon:

Yeah. That's great, Joe.

Joe O'Connor:

I would just say, do it. It's going to be the most difficult at times and the most rewarding all the time experience that you're going to have, you're going to meet people that are going to not rely on you, but they're going to be really, really interested in understanding what other people are doing out there. And don't be afraid to let people come up with their ideas. We've had it was a gentleman whose wife had trouble turning in bed. She would always pick up static. So, he found a way of getting her a grounded blanket, which is a blanket, which is the ground, ground plug on it. Never heard of that before in my life, but it was really, really something. So, I mean, I just say, be ready for an experience. That's going to be fantastic.

Melani Dizon:

Love that, Carol, that you will be appreciated. You may not feel it right away, but you will know that those people in your group appreciate your efforts and the time that you've taken Greg.

Greg Richard:

I'm into free drugs. And when you help other people, you're emitting serotonin. There is no more powerful, happy drug That's true than serotonin cost you nothing but your time and you're helping another person. The one other thing that I would mention is we have a whole list of what I call tricks of the trade. It's a whole little section that we talk about. So, whether it's safety around the house or any issue we share, what are the tricks of the trade? You know, nobody's been doing this long enough with Parkinson's to write everything down. So just share what you've learned that you know, writing a will you know, setting it, getting your finances in order, whatever the people want to talk about. And then keep track of those. I sent to you earlier, before we started Mel, a whole list of things that I use when I'm helping a new support group get started here.

And so, feel free to share that with whoever you want to, you know, share with. Oh, great. You don't need my permission. Just send it out to people. But I think, you know, somebody, all of us that have Parkinson's are in this to defeat this, this disease in our generation. I know I am. There's no reason this needs to keep dragging on. We just need to start getting the funding and the awareness, the research and what are we doing to help everybody else with Parkinson's live a better life. And so, to me, that's the ultimate goal of what a support group is about. And so, anything that I can share with and, you know, and help anybody else, I'm happy to do it.

Melani Dizon:

Right. Thank you, Joe.

Joe O'Connor:

Just one last comment from me. Be sure to check out the larger organizations. The Phinney Foundation can help you a great deal. The PMDI Foundation can, has monthly meetings for



support group leaders where they can just get together and chat. Be sure to use those to your advantage as well. You know, don't, don't just limit yourself to looking around your area. There are much bigger organizations. Parkinson's Foundation, and the APDA, they all have programs to help support group leaders and take advantage of them.

Melani Dizon:

Yeah. And you've got, you know, eight people on the screen who know a lot about what they're doing. So, we'll put the, we'll put the link in the chat if anyone wants to reach out to one of you. Thank you all so much for your time. That was really great. I know people are going to be so grateful for the advice that you've offered, the support, and the encouragement, and I will put a lot of links in the show notes for this. So, thank you, Patty, Carol, Michelle, Stan, Joe, Patty, Doug, and Greg. And Greg, we wish you the best tomorrow morning with your DBS. We hope to have an update and yeah. Thanks, everybody.

Joe O'Connor:

Thank you. Thank

Melani Dizon:

You. Thank bye. Have a great day.

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