



## **ADA Live! Episode 116: Understanding and Finding Support for Parkinson's Disease**

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**Guest:** Ann Marie Worman, Executive Director of Parkinson Association of the Carolinas (PAC)

**Host:** Janice Baldon-Gutter, Program Outreach Coordinator for Diversity, Equity, and Inclusion for the Southeast ADA Center

**Moderator:** Barry Whaley, Project Director of the Southeast ADA Center

**Recording:** [adalive.org/episodes/episode-116](https://adalive.org/episodes/episode-116)

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**Ann Marie Worman:** Hi, I'm Ann Marie Worman and you're listening to ADA Live.

**4 Wheel City:** Yo. All right. Let's roll. Let's go.

**Barry Whaley:**

**Barry Whaley:**

Hi, everybody. On behalf of the Southeast ADA Center, the Burton Blatt Institute at Syracuse University, and the ADA National Network, want to welcome you to this episode of ADA Live. I'm Barry Whaley. I'm the project director here at the Southeast ADA Center.

Listening audience if you have questions about the Americans with Disabilities Act, you can use our online form anytime at [adalive.org](https://adalive.org), or you can call the Southeast ADA Center at (404) 541-9001. And remember, those calls are always free and they're confidential.

On this episode, we're going to be talking about Parkinson's Disease, and according to the Parkinson Association of the Carolinas, Parkinson's Disease, or sometimes known as PD, is a brain disorder that affects nearly 1 million people in the United States.

Interestingly, that number is expected to rise over the next seven years to 1.2 million.

Parkinson's is the second most common neurodegenerative disease after Alzheimer's disease, and our guest today is Ann Marie Worman. She's the Executive Director of the Parkinson Association of the Carolinas. And our host for today's episode is Janice Baldon-Gutter. Janice is the program outreach coordinator for diversity, equity, and inclusion here at the Southeast ADA Center. And it's appropriate Janice is hosting today because she was a caregiver for her brother Virgil, an Air Force veteran who developed Parkinson's disease. Sadly, Virgil passed away in 2019.

I want to welcome you to the show, Ann Marie and Janice. And Janice, I'll turn it over to you.

**Janice Baldon-Gutter:**

Ann Marie, welcome to ADA Live. We are so glad you could be with us to talk about your organization, Parkinson Association of the Carolinas, and the concerns of people with Parkinson's Disease. To begin, can you please tell us what is Parkinson's disease and what are the causes?

**Ann Marie Worman:**

Sure. Thank you, Janice. So Parkinson's disease occurs when brain cells that make dopamine, which is a chemical that coordinates movement in the body, either stops working or dies. So that's the important thing, is dopamine. As the dopamine levels continue to decrease, that's when you'll see more and more signs of Parkinson's disease physically and non-physically. What are the causes? It's unknown, basically is what you'll hear from most experts, the cause. But I think Michael J. Fox Foundation sums it up best when they say if there was a continuum for Parkinson's disease with genetics on one end and environmental factors on the other, most people with Parkinson's would fall in the

middle at many places. So that sounds kind of like a convoluted answer, but there just really is no one or two causes of Parkinson's disease.

**Janice Baldon-Gutter:**

Thank you very much. Ann Marie, is there a genetic link to Parkinson's disease?

**Ann Marie Worman:**

There is a gene associated with Parkinson's disease and there is genetic testing that someone who has Parkinson's can undergo and determine if they have that gene, in fact. If they do discover they have it, it's a pretty good indicator that their children and potentially siblings, but a lot more their children could have Parkinson's disease as they go through their life.

So what they do is they then arm that person with that information, "Hey, your mom, your dad has this gene, you probably want to get tested," and then they urge them to go get genetic testing. I do know that some people choose not to, because they don't want to know that they have it and feel like they're constantly waiting for it. And other people have gone on and said, "Nope, I want to know so that I can plan ahead for down the road in case that happens to me." So it can be a great tool for folks who have Parkinson's to find out whether they do carry that gene and can let their family know

**Janice Baldon-Gutter:**

That's valuable information. Thank you very much.

**Ann Marie Worman:**

You're welcome.

**Janice Baldon-Gutter:**

What are some of the symptoms of Parkinson's disease?

**Ann Marie Worman:**

Sure, so that's where it gets to be a little more tricky, and I think what I've learned over the years is not everyone with Parkinson's disease is going to experience the same symptoms. They're different for different people. You'll see that in a lot of your chronic medical conditions. Not everyone with diabetes will have all the same symptoms. Sometimes it can be even hard for your specialists to detect, while others are obvious even to an untrained eye.

For instance, motor symptoms, those are the most recognizable. Those are the things like what's called a resting tremor, where there's shaking that occurs in a hand or a limb when it's relaxed and disappears during movement. You'll have slowness, which is a spontaneous and a voluntary movement that may include slower walking, less arm swinging. And then stiffness, which is basically muscle stiffness called rigidity, which can be detected by a doctor on examination.

However, there's a lot of non-motor symptoms which aren't physically recognizable. You can't see those by just looking at someone. And those are things like low blood pressure, constipation, sweating problems, excessive perspiration, urine problems. So these are the kinds of symptoms that really start out first for Parkinson's disease. And as you could probably imagine, a lot of those symptoms go diagnosed as something else completely, because just you have low blood pressure, no one's going to think about Parkinson's. So this is why the disease is so hard to diagnose as well.

**Janice Baldon-Gutter:**

Ann Marie, please tell us more about the services and programs of your organization, Parkinson Association of the Carolinas.

**Ann Marie Worman:**

Sure. So we're an independent local organization that provides resources and assistance to people with Parkinson's, the people who care for them, and the healthcare community. We do this through education, by educating all of those different groups on what is Parkinson's disease, what they can do for themselves, what the healthcare community can be doing. We offer education opportunities in the way of workshops, annual

symposiums, webinars, lots of different opportunities for people to learn more. We do that with visiting support groups and managing support groups. We probably have about 60 across both the state of North Carolina, so we provide that support to North Carolina and South Carolina communities.

We also do that through exercise classes, which are sometimes referred to as movement therapy, and we offer free yoga, free dance for Parkinson's, and free pedaling for Parkinson's, which is a cycling class. We offer care advisors who answer our phone line and are able to listen to that person with Parkinson's or listen to that person who's caring with them and what their frustrations are or what their struggles are, and try to help them with a plan by referring them to resources.

It could be physical therapy, it could be speech therapy, it also could be a specialist. Not many people understand that there is a specialist for Parkinson's disease and they're called movement disorder specialists. They are neurologists who went to two years of extra training to treat people with Parkinson's disease and other movement disorders. I always try to tell people if they're able, and it's not a huge inconvenience time-wise or distance, to try and get an appointment with a movement disorder specialist. So these are the things we advise people on, trying to educate them about the disease, about the symptoms, and then pointing them in the right direction for the resources that can be most helpful to them.

**Janice Baldon-Gutter:**

Thank you very much. According to the Michael J. Fox Foundation, estimates suggest that Parkinson's disease affects nearly 1 million people in the United States and more than 6 million people worldwide. In addition, a 2022 study from the Michael J. Fox Foundation found that nearly 90,000 people are diagnosed each year with Parkinson's disease in the United States. This number represents a steep 50% increase from the estimated annual rate of 60,000 diagnoses based on a series of previous studies. Why have we seen such a steep increase in the number of people diagnosed with Parkinson's disease?

**Ann Marie Worman:**

Sure. So I think there's several reasons. One obviously is that Parkinson's disease tends to be thought of as an older disease that you really don't get diagnosed with it until maybe you're in your mid to late fifties or sixties. And we have that population that's growing in size anyway, and therefore a lot of researchers and doctors seem to think that's a reason why.

I also believe, in my opinion, so many more people in their fifties and sixties and that age group becoming larger in population are so savvy about their health nowadays. They're really clued into things that are happening with their bodies, and so maybe not with those non-motor symptoms, but with those motor symptoms, I mean, as soon as someone sees a tremor, it seems like they're calling their doctor up nowadays. As soon as they feel like, "My walking seems weird," they're calling a doctor up. Well, I think that that has a lot to do with it as well, that we're just more educated and getting more familiar with really being on top of our health, and people are reaching out to their providers and specialists regarding those symptoms.

I think that there are also hopefully more instances of Parkinson's disease being put out there into the community in different marketing scenes like us. We're constantly going out to groups and talking about Parkinson's disease and getting people familiar with what it is, and you're seeing commercials on television for various pharmaceutical products about Parkinson's disease and how it can help symptoms. And I think all of those things together are increasing people's awareness, thereby increasing the amount of cases being diagnosed.

**Janice Baldon-Gutter:**

Fantastic. Are there groups of people or populations who are more impacted by Parkinson's disease?

**Ann Marie Worman:**

I don't know if there's any specific groups that I'm aware of, other than the fact that it seems like men end up getting Parkinson's more often than women. The ratio is more men to women. I know that we have some disparities as far as groups who are underserved, and a lot of that is your African-American communities, communities of color, who just aren't out there in maybe some of those situations or places where the Parkinson's is being discussed or where it's being promoted for them to have an idea of what might be going on with them or a loved one. But there aren't any specific groups of populations who are more impacted than others.

**Janice Baldon-Gutter:**

Do we know why Parkinson's disease might affect these groups of people or populations more often?

**Ann Marie Worman:**

I haven't read anything specific why men more so than women, so I don't have anything to kind of give to that. I have not heard the statistics around why men are more diagnosed. It just seems like as they're doing the research on the actual numbers as reported by healthcare facilities and doctors, that that seems to be the ratio of more men than women.

I often wonder if women are less because they're so busy caring for everyone else that they ignore some things, where a man, the same person, a woman caring for the man who might be getting Parkinson's, might be pointing out those symptoms and saying, "I think we should go get that checked." I've also heard of that just in my experiences with talking to women, but that's my opinion based on some we've talked to.

**Janice Baldon-Gutter:**

Thank you. Please tell us about the Parkinson's Prevalence Project from the Parkinson's Foundation. Why is this project important?

**Ann Marie Worman:**

So this project dealt with taking some statistics about Parkinson's that they learned what areas of the US had numbers of Parkinson's disease in, for instance, different states. What were their Parkinson's numbers and why is it important to know these things and why do we want to keep track of them? And so if you look at the study, it does talk about what was mentioned earlier, that by 2030, in a mere seven years, which, that number sounded so far off until Barry said seven years, it's estimated that 1.2 million Americans, not people around the world, but Americans, will be living with Parkinson's disease.

So some of the things they did was just kind of go by different states, different counties. So it became important, the report, for really healthcare people to really zone in on why those areas were higher, how those numbers came about. But the idea is that the differences might be due to access to doctors with greater experience in diagnosing Parkinson's or a higher rate of environmental and genetic risk factors in certain areas.

So that's kind of where they were able to hone in. Really helps the healthcare community and people like us try to understand why certain areas might be higher than others, and if others aren't high, why is that? Do they not have access to healthcare specific for Parkinson's and what can we do about that? So I think that it just really helps all of us be able to parse out that information and figure out how can we do better at knowing what's going on in these different areas.

**Janice Baldon-Gutter:**

Now that we know more about the symptoms of Parkinson's, what are some of the treatments that are available?

**Ann Marie Worman:**

Yes. What can we do? So when someone goes in and they get that diagnosis of Parkinson's disease, the first thing most times they're given is a prescription for a drug called carbidopa/levodopa, and it helps the dopamine, which, as I discussed earlier, is declining in people with Parkinson's. So that drug helps to pump it up a little bit so that maybe they get some relief from the symptoms they're experiencing. And it only lasts a few hours or several hours depending on the person, and that's called on times like, "I'm



on it. I'm great. My medication's working," and then when it starts to deplete and start to wear off, you go into what's called an off time.

So there are a lot of medications that have come out just over the last few years for Parkinson's. They treat the movement piece of it, they treat the delusions and hallucinations that we know occur with Parkinson's. They can help with the slowness, they can help with the stiffness. There's a lot of different medical treatments out there and a lot of different ways to get them. There's pills, there's inhalers, there's injections, and there's even a pump directly into the stomach because, as I mentioned, a lot of researchers feel that Parkinson's starts with the gut and this way if you're taking the medication directly into the stomach, it's directly being distributed. It's crazy all the different ways you can receive your medication.

Some other treatments that are not medication oriented are medical devices. One of those is deep brain stimulation, or known as DBS. That is an actual brain implant. It's fantastic. If you Google it, you will probably find a video on an actual implant. It's fascinating to watch. Basically it's two rods and connecting wires that are placed in the brain at the top of the head, and then the leads are worked down the side of the brain, behind the ear, down the neck, into the chest to a receiver much like a pacemaker. And then there's a remote device that can actually control the brain implant, and it gives that person a sense of being able to control how much of a change they need in the wires in order to address their symptoms.

I've seen someone who had speech issues during a meeting, they could tell their speech was getting worse. They took out their device, they pressed a button until they got to the right setting, and then within a moment or two, their speech was perfectly fine again. It's an amazing, incredible device. A lot more people are opting for it. You have to be a good candidate though. Not everyone is a good candidate for that type of medical device.

As far as other treatment, we also highly recommend, and so do movement disorder specialists, exercise. We can't talk enough about how much exercise can increase someone's dopamine levels on its own. I have folks who take their medication and then they make sure they're in an exercise class that starts before their medication and wears

off and they don't have to take any more medication because the exercise bumped up their dopamine enough. So exercise has been proven through scientific research and studies to definitely increase dopamine on a short-term basis, but allows someone to experience a longer quote "on time." So exercise is key. And that can be anything from pedaling, from bicycling to yoga to specific classes designed for Parkinson's, such as power move with Parkinson's, rock steady boxing for Parkinson's. So it's a great combination of medication, medical therapy, and physical therapy for someone with Parkinson's to really help all of those various symptoms that they can experience.

**Janice Baldon-Gutter:**

My brother chose to have the brain stimulation, and it did help. Yes. We were really reluctant. We wanted for him not to choose that, but that was his choice and it did help.

**Ann Marie Worman:**

Good. Good. It's always wonderful, of course, when it makes a difference. I've only known, I mean, not even a total of fingers on one hand the people who it has not worked for and they had it removed. Otherwise, almost everyone I know that I've seen or talked to it has helped in one way or more.

**Janice Baldon-Gutter:**

Can you please tell us about some of the research being done for Parkinson's disease?

**Ann Marie Worman:**

Sure. There's some really great research, the last time I looked, that Michael J. Fox is doing about a medication that would stop Parkinson's. So while we haven't found anything to cure it, they're working on something that looks like it could stop it. So obviously someone is still going to get diagnosed with Parkinson's disease, but if they get diagnosed early enough, they would be able to take that drug, depending on the way it's formulated. It could be a drug, it could be an injection, I don't know. But whatever this ends up being, they could take it and it would stop the disease from progressing, which would be huge in itself. If you can't cure it quite yet, that would be the next best thing,

because so many people look ahead to someone else who's had Parkinson's and maybe how they are experienced was and they, "I can't even think about that. I don't want to think about me being at that point."

So if that were to come to fruition, then that would be amazing to be able to stop it where it was at and not have it progress. Of course, there's always lots of research in new ways to deliver medical treatment for Parkinson's, something that works, but also something that's easy for people to use. I think one of the latest things is a drug, and it's one of the best things lately, because most of your pill forms for Parkinson's have to be taken just the way they are. So then you just have to adjust doses. This pill can actually be broken up into four pieces so that you can literally start out with just one or two pieces, so half the pill, we're going to start with. Well, you know what, you need a little bit more. Instead of doubling it like you might have to with other medications, you can just break off another piece of the pill and you can add that and see how that works.

So it's a wonderful newer medication. A lot of the doctors like it. A lot of the movement disorder specialists are telling their patients about it because of its ease in increasing the dose and the ease for people to be able to take it. So still a lot of research too around gastroenterological studies about Parkinson's starting in the gut and what are they identifying? It could be a cell or a gene. And they do, of course, continue to do a lot of research in genetics with Parkinson's.

**Janice Baldon-Gutter:**

As we mentioned in the introduction to this episode, I was one of the family caregivers for my brother, Virgil, who developed Parkinson's disease. How does Parkinson's disease impact the lives of caregivers and families?

**Ann Marie Worman:**

Oh my goodness. Well, you probably should talk to this, Janice, but oh goodness. I don't think caregivers realize how much it's going to impact. Especially a spouse, because a spouse is living with them all the time. They're there 24 hours a day. And you may have been the same way with your brother, everybody's situation is unique. But it's going to

affect them in the sense that... This is what I tell people, the caregiver, you have to imagine that you have Parkinson's as well, because you are in this journey and in this fight with them. So you are breathing it, you're living it 24 hours a day.

We have a lot of caregivers who attend our classes with the person with Parkinson's, and we love it and we encourage it. That way they see what they're doing, they know what they're doing so if they want to take it home and do it, they can. So on the positive side, we as an organization are treating them a lot like the person with Parkinson's. We're making sure that they have access to all the resources they need.

One of the things that people who care for someone with a chronic medical condition like this, they forget about themselves, and so they forget to take care of themselves because they're focusing 100% of their energy on caring for that person. And then that caregiver, they get sick, they're not taking care of themselves, and if they get sick and they're not taking care of themselves, who's going to help that person with Parkinson's? So it impacts them emotionally, mentally, it impacts them physically, with their health. Financially. I mean, we know Parkinson's is not an inexpensive disease, much like a lot of your chronic medical conditions. Medications are expensive, treatments are expensive, physicians are expensive, and insurance has gotten a lot better about what they do cover.

But those are just a few of the ways. A lot of folks have to change the way their home is laid out for a person with Parkinson's. You may have to give up something that you enjoy doing because your person with Parkinson's cannot do it any longer and it was a joint thing, a joint activity. But I encourage all my caregivers to please set aside some time every day to do something for yourself. Whether that's, "Okay, you're settled in for right now, you don't need anything? Great. I'm going to go in the other room and I'm going to read my book for 30 minutes." Just you've got to give yourself time, you have to give yourself grace, and you have to reach out.

A lot of times the person with Parkinson's get so defeated by their diagnosis and the outcome they think is going to happen, that they get depressed and they act out against their caregiver. So we also are here for the caregivers. We want to talk to them, we want to listen to them, we want to help them, and we want caregivers to know that you are just

as important as this person with Parkinson's, because you are their link to their health, to getting the care they need, to being where they need at the right time.

So it impacts the lives of caregivers greatly, and especially if you are diagnosed with young onset and you have young children. I have to say, I have been witness to several people who had teenagers and those teenagers were rolling up your sleeves, "What do we need to do? How do we need to help? Do you have to have a certain diet? Do you have to have a certain medication?" So those children took it upon themselves to be caregivers, because families are in the most positive way, and I've seen that over and over.

So I just want families and caregivers to know it's hard and it doesn't get easier with the disease because the disease progresses, but you have to work as a team and you have to approach it as a team. And I think if you do that, it just makes it a little bit easier. I'm not going to say it makes it easy, just makes it a little bit easier if everyone comes at it from that approach.

**Janice Baldon-Gutter:**

I identify with that. My sister and I led the march. He has children, but my sister and I led the march to get him moved into a safer environment [inaudible 00:29:55] all work together as a team, and we got him in an environment where he can maintain his independence, but a safer environment for him.

**Ann Marie Worman:**

That's what it takes. And that was a great outcome, I'm sure, for him to be able to do that.

**Barry Whaley:**

Thank you Ann Marie and Janice. ADA Live listening audience. If you have questions about this topic, or any other ADA Live topic, you can submit your question online at [adalive.org](http://adalive.org) or you can call Southeast ADA Center at (404) 541-9001. And now a word from this episode's sponsor, the Parkinson Association of the Carolinas.

**Commerical:**

The Parkinson Association of the Carolinas, or PAC, is an independent regional nonprofit that serves the Parkinson's communities across the Carolinas. Their mission is to empower individuals and families living in the Carolinas who are affected by Parkinson's disease through education, outreach, and direct support. They have been supporting the Parkinson's disease community for over 20 years and look forward to their next 20. Unless a cure is found. For more information, contact the Parkinson Association of the Carolinas at 1(980) 245-2786, or visit their website at [www.parkinsonassociation.org](http://www.parkinsonassociation.org).

**Janice Baldon-Gutter:**

Welcome back to the show everyone. I'm Janice Baldon-Gutter with the Southeast ADA Center. Our guest is Ann Marie Worman, Executive Director of Parkinson Association of the Carolinas. We've been talking about the concerns of people diagnosed with Parkinson's disease and how families and caregivers can help. Now let's talk about the rights of people with Parkinson's disease under the Americans with Disabilities Act, or ADA.

The ADA defines a person with a disability in three ways. Number one, as someone who has a physical or mental impairment that substantially limits one or more major life activities. Or number two, they have a record of such an impairment. Or number three, they are regarded as having such an impairment. In most, but not all cases, Parkinson's Disease meets the definition of disability under the ADA. Workers with disabilities who are covered under the ADA are protected from discrimination that is based on their disability. People with Parkinson's disease may experience symptoms that may or may not affect their ability to do their jobs.

What are some of the issues that workers with Parkinson's disease might face?

**Ann Marie Worman:**

Sure, thank you, Janice. That is a real sticky situation. So many people are afraid to mention their Parkinson's to their employers for fear of what might happen. So I always

tell people, and again, experts in the field say that a lot of people hold off until their symptoms just become very noticeable, and then they go and they tell their folks and they tell them, "Here's the thing. I have a Parkinson's diagnosis. However, my physician and myself don't feel that it's going to keep me from being able to carry out the scope of my work that I do here."

And I think that's the key, is if they're able to continue to do the scope of the work. So I'll give a couple of examples, if that's okay. I had met a gentleman who was an OBG/YN doctor and he had developed Parkinson's and he went to his partners and told them that, "I've been diagnosed with Parkinson's, but I've started to develop a tremor. I'm going to take myself out of the hospital labor and delivery rotation, because I just don't think that's probably a good idea. So I'm just going to see patients in the office and that's what I'm going to do."

So that was fine. He did that well. He explained to all his patients, all of his patients were fine with it, no one had a problem. But on the backend, his partners decided to figure out a way to remove him from the practice because they were afraid of what type of liabilities might happen, and they just didn't want him working, even though that he was perfectly fine with what he was doing. He wasn't putting anybody's health in jeopardy. He wasn't doing anything that would be libelous.

So he did sue them and he won, because the physician was able to prove that this is what he does for his job and these things aren't affected by this, and he also had some folks from the office speak up on his behalf. And then he went on to just sort of go around and talk to Parkinson's groups about how you have to advocate for yourself and explain what's happening and what's going on, and fight for yourself and fight for your job, if that's what you want.

I do know that, as I mentioned, symptoms are going to vary for everyone. So the severity of your symptoms are going to going to decide whether you can continue to do your job. Some people are still working after 20 years of their diagnosis because their Parkinson's hasn't progressed as far as other people with Parkinson's disease.

I know that a gentleman who works in the financial world, all of his are physical in the sense of his walking, leg movement, those things, but he has no hand tremors, no speech issues, and so he's still able to do his job because most of his job is talking with people and meeting with people, so he's able to carry on his job. There are a few people who have had some severe speech issues, and because they had a job that really entailed them speaking to clients or doing presentations, they did have to back away and not be able to do that.

So I think it all boils down to knowing what you do, what your job description is, speaking with your physician about the things that you do, and getting a statement that you can still do them. And when you're ready to tell your employer about your Parkinson's, that you go to them with that conversation and let them know that, "This is what I have going on. This is what my physician has said." Some people with PD may not realize that other folks around the office have noticed something and are wondering what's going on. And so having a conversation with your employer could actually be a relief for both people, because now it's like, "Okay, now we understand. Now we get it." And it can open the door to the employer making accommodations that could allow you to continue your job where maybe you thought, "There's nothing they can do for me. I'm going to have to quit my job."

So I always encourage people to have the conversation, either with their direct supervisor, employer, or with their HR person, so that you can get that out there and get ahead of it.

**Janice Baldon-Gutter:**

You gave us an example of an experience with a person trying to continue to work and manage their Parkinson's when you were talking about the doctor. How often do people with Parkinson's disease continue working after being diagnosed?

**Ann Marie Worman:**

Sure. Gosh, it really just depends. I know people who were diagnosed in their early forties and into their late fifties are still working, because it all boils down to your symptoms,



really. What are the symptoms that you have? If you're a physical trainer and you're walking slow and you're having rigidity and stiffness and tremors, you probably can't continue to do your job very often because it is a physical job.

So it really boils all back down to the symptoms. As I tell people, always remember, your disease isn't going to be the Parkinson's person's next to you disease. You guys might have different experiences, different symptoms. You might not ever use the same medications. It's all going to look very different. Not necessarily a one size fits all diagnosis at all, and it's not a one size fits all treatment or how to handle different scenarios. I think people can go 10, 15 years, just depending, again, what their job is and how their symptoms of Parkinson's are affecting them.

**Janice Baldon-Gutter:**

According to the Job Accommodation Network, or JAN, people with Parkinson's disease may develop functional limitations such as fatigue, memory, or balance issues, and the degree of limitation will vary among individuals. Not all employees will need accommodations to perform their jobs, and others may need only a few accommodations. What types of job accommodations are typically needed by workers with Parkinson's disease?

**Ann Marie Worman:**

So types of job accommodations that might be typically needed by workers with Parkinson's disease could be, if you're able and you have this kind of relationship, to be able to leave your job at a certain time during the day to go to a rock steady boxing class or to go to a Parkinson's exercise class that's only offered during that time and maybe rework your schedule for that day. I know quite a few people who have worked that out with their employers and it's worked out well.

Other accommodations might be that standing works better for you than sitting at your office space. So maybe you can work out the accommodation of having a rising desk where it goes up and down, because maybe when you start to get that rigidity that you have to maybe stand up and move it, shake it out a little bit.

So there's a lot of different things that you may think, "Well, they can't do anything for me." Well, talk to your physician and find out, "What kind of accommodations do you think could be made for me to be able to do this part of my job?" And sometimes they're the best people, or if they have a social worker that works with them, they can help you brainstorm those things. We could help you brainstorm those things. Ask. It doesn't hurt to ask, with the old adage, all they can do is say, no, we can't make accommodations for you. And then you have your decision on what you need to do.

But as far as like seating, standing, taking a break at certain times of the day, I've heard of those, working remote, maybe, because that might be easier for you to manage your Parkinson's at home rather than in the office. So those are just a few things that I've seen put in place myself.

**Janice Baldon-Gutter:**

What forms of discrimination may people with Parkinson's disease face in their daily lives, such as when shopping or traveling, and what are some strategies when these issues occur?

**Ann Marie Worman:**

I don't see a lot of discrimination. I'd say more of an accommodation thing, where people just don't pay attention to the fact that you're freezing. Now, freezing for a Parkinson's person can happen just trying to enter a doorway to a business. For some reason, the brain looks at that entryway and that little metal strip across there that most doorways have as a barrier, and so their brain won't connect and let the body move, and they could stand there for 10 minutes. And people are insensitive, they don't understand, "Why are you blocking the door? I'm trying to get in." So I think that if someone says something to the person with Parkinson's, "Excuse me, is there a problem?" Even if they're saying it kind of snarky, the person with Parkinson's has to speak up and advocate and say, "I'm sorry, I have Parkinson's disease and my body just can't move. It's going to take me a little while." "Oh, can I help you? Can I get you into the door?" "No, no, no, that won't help. I just have to do this myself."

So I think if someone approaches someone in that instance, where they physically see something's going on, what's the problem? Why are they slow? Why are they holding me up? And they say something, then that's helps the person with Parkinson's advocate for themselves.

Otherwise, I think that with traveling, a lot of it can be you are really going to have to manage your travel with Parkinson's. You're going to have to, again, be proactive and think about, "All right, am I going to need an aisle seat because of some issues I have with my leg? Do I need a special accommodation to be at the front of the plane versus the back of the plane? Do I need to be near the bathroom?" So I think that it falls a lot on the person with Parkinson's and their care team, family, friends, to really plan ahead, be proactive about thinking about what you need while you're out doing those things.

As far as shopping, it could be that maybe it's easier for someone to use one of the battery operated carts for shopping with Parkinson's if they're slow or experiencing a shuffle in the way they walk. It helps them, and then it will also help everyone around them. I think that's where I just really try to tell the people they need to be proactive when they're planning to go out somewhere if they're having physical limitations already.

**Janice Baldon-Gutter:**

Thank you so much for the great information you've shared with us and our listeners about Parkinson's Disease. The ADA rights of persons with Parkinson's, and their support caregivers and families who are dealing with Parkinson's. I wish we'd had this information to this degree when we were working with my brother. To learn more, how can they contact your organization, Parkinson Association of the Carolinas?

**Ann Marie Worman:**

I'm sorry you didn't have that information. That's why we're here, especially for the Carolinas, to make sure people have it and know that they can call us. But we also get, it's very interesting, people from out-of-state calling about friends and family in the Carolinas, so help people wherever. So yes, if they'd like to learn more, there's two ways, they can call us directly and a care advisor will talk to them and provide them with as

much resource information as they can. And that number is (980) 245-2786. There's also a toll free number, which is (866) 903-7275, and I know that'll be furnished later as well. And then our website is Parkinson, there's no S on the end, so parkinsonassociation.org. And if you go there, we have a whole section just on understanding Parkinson's, but we also offer virtual exercise classes, virtual support groups, virtual wellness Wednesday groups. So anyone from anywhere can join and take part in some of our programming.

**Janice Baldon-Gutter:**

That's great. My brother had his surgeries in the Carolinas, so we're very happy. Yes.

**Ann Marie Worman:**

Wonderful.

**Janice Baldon-Gutter:**

Yes. Ann Marie, thanks again for being with us today to share this important information. Barry, I turn the mic back over to you.

**Barry Whaley:**

Thank you, Janice. Listeners, you can access all ADA Live episodes with archived audio, accessible transcripts, and resources at our website, [adalive.org](http://adalive.org). You can listen to the SoundCloud ADA Live channel. That channel is [soundcloud.com/adalive](https://soundcloud.com/adalive). You can download ADA Live to your mobile device. From your podcast app, search for ADA Live.

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Cheri Hoffman, Mary Morder, Marsha Schwanke, Chase Coleman, and me, I'm Barry Whaley. Our music is from 4 Wheel City, the Movement 4 Improvement.

We also invite you to tune in to our companion podcast, Disability Rights Today, for an in-depth discussion on important court cases that shape disability rights and the Americans with Disabilities Act. You can learn more and listen at [disabilityrightstoday.org](http://disabilityrightstoday.org). See you next episode.

#### **4 Wheel City:**

They watching. They don't want us be part of the city, man. They put all these steps, man. All these curbs we can't get over. All these inaccessible stores. 4 Wheel City. They don't want us here. We'll survive and we're going to make our own place. Our own world. The 4 Wheel City-

[End of Transcript]

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