apda AMERICAN PARKINSON DISEASE ASSOCIATION
Strength in optimism. Hope in progress.

Spotlight on Living Your Best Life:
Accessing the Treatments You Need

Transcript

Welcome and Introductions

Rebecca Gilbert, MD, PhD

[Slide 1] Welcome everyone and thank you so much for joining us today. **[Slide 2]** My name is Rebecca Gilbert, and I am APDA's Vice President and Chief Scientific Officer. I'm pleased to welcome you to this web teleconference education program designed for people with Parkinson's disease (PD), care partners, family members and healthcare providers. I would like to thank the Simone Charitable Foundation for funding this important program and acknowledge their appreciation for the critical need to provide educational programs like this one to people impacted by Parkinson's disease.

During this time of uncertainty, we know that you may still have concerns regarding your Parkinson's treatments and of identifying ways to continue to live your best life with Parkinson's disease. American Parkinson Disease Association, or APDA for short, is the largest grass roots network dedicated to fighting Parkinson's disease and works tirelessly to assess the approximately one million Americans with Parkinson's disease. APDA distinguishes itself as a national organization working one on one with the Parkinson's community to make each day better.

After the presentation today, we'll open up the program for questions from both telephone and web participants. At any time during the program, you can submit your question using the Question-and-Answer tab in the lower left-hand window on your screen. We encourage everyone on the line to complete the evaluation after the program because your feedback is instrumental in helping us plan for future educational offerings, including teleconferences like this and other programs.

Presentation

Rebecca Gilbert, MD, PhD

[Slide 3] Now to our program. I would like to welcome Annette Kluge, Associate Director, Outreach at Banner Neuro Wellness in Gilbert, Arizona, and Joanne Ruelas, Licensed Master Social Worker, Patient Navigation and Outreach at the Barrow Neurologic Institute in Phoenix, Arizona. They're joining me today to share the latest information on accessing the treatments you need for Parkinson's disease. I'll begin by presenting the basic facts of Parkinson's disease and an overview of the medical treatments available.

[Slide 4] Here are my financial disclosures. **[Slide 5]** And now let me begin.

Parkinson's disease, as most people who are listening likely know, is a very complex neurologic disorder and involves a combination of both symptoms that affect movement of people as well as many symptoms that affect other parts of function. So, let's start by discussing the motor symptoms of Parkinson's disease. There are four key features of Parkinson's disease. The first is tremor, which is a shaking movement that typically involves the arms, sometimes the legs and it typically happens at rest when your hands are in your lap or dangling at your side as you walk. The next key feature of Parkinson's is rigidity or stiffness of the limbs usually. And then there's also slowness or what we call medically as bradykinesia. And, finally, there are typically problems with balance and inability to right yourself if you're thrown off balance.

In addition to these four what we call the cardinal features of Parkinson's, there's some other features that are very classic of Parkinson's disease and those include a soft voice, a masked face which means a face that doesn't show a lot of expression, small handwriting, difficulty with fine motor tasks and stooped posture.

[Slide 6] But in addition to these motor symptoms, those symptoms that involve movement, there are many symptoms that do not involve movement that involve other aspects of function. We often compare the motor and the nonmotor symptoms of Parkinson's disease to the part of the iceberg that's above the water and the part of the iceberg that's beneath the water. The motor symptoms are the symptoms that people can see. People can see your tremor, people can see you're slow, people can see that you don’t have expression on your face and those would correlate to the part of the iceberg that can be seen. But beneath the water, there might be a huge chunk of the iceberg that can't be seen but can be very problematic in and of itself, and those would be the non-motor symptoms.

We typically classify these non-motor symptoms into three big categories – the neuropsychiatric category. These are the conditions that might affect your mood, your cognition or thinking abilities, sleep, your motivation, or apathy. The second big category are the autonomic symptoms, and these are symptoms that affect body processes that we don't typically control consciously, like blood pressure control, gut function, urination function and sexual function. And the third category are sensory symptoms, and this can be symptoms that involve vision, symptoms that involve pain sensation or symptoms that involve smell.

[Slide 7] Before we talk about anything else, I want to really put up and center to this talk the importance of exercise in the life of somebody with Parkinson's disease. There has been much study of exercise in Parkinson's disease, and we have lots of data that shows that exercise can help a person manage motor and non-motor symptoms of Parkinson's disease and improve quality of life. We know that being sedentary, being deconditioned, not being in a fit body can increase the stiffness, can increase the stooped posture, and can lead to even more poor endurance, and all this together can make Parkinson's disease harder to live with. And so, focusing on exercise and moving is so vital for somebody with Parkinson's disease.

Now where to begin if you are somebody who needs to exercise? Well, let's start with the CDC, the Center for Disease Control, recommendations of 150 minutes of moderate intensity or 75 minutes of vigorous intensity exercise per week. That's what's recommended for all older adults, including those with Parkinson's disease. And this may need to be modified as you discuss with your doctor what might be a good regimen for you. But when you come up with a regimen of exercise, you want to think about the four key features of exercise. And those include aerobic activity, and that's the type of activity that gets your heart rate going; strengthening activities, and that may involve weights; stretching activities as well and then, finally, balance which is hugely important for somebody with Parkinson's disease.

[Slide 8] Another thing that is within our control besides exercise and moving is diet. And dietary considerations for Parkinson's disease is extremely important as well. There has been a lot of study on the effects of the Mediterranean diet on somebody with Parkinson's disease and this is a diet that's rich in vegetables, rich in fruits and whole grains, rich in legumes such as beans, peas, and lentils, nuts as well as low fat proteins such as fish and poultry. In addition, the fat source in a Mediterranean diet is primarily olive oil.

There are some dietary considerations that one also needs to think about in terms of Parkinson's disease, and one is that dietary protein can compete with levodopa, which is one of the key medications for Parkinson's disease, to cross the small intestinal wall and that might make medication dosing less effective if dietary protein is in the way. And so, that's something to consider and discuss with your doctor.

And, finally, there's some other key symptoms of Parkinson's disease, such as low blood pressure or weight loss or constipation that can be helped with the proper diet. And so, diet is another way that we can help ourselves in our Parkinson's disease treatment.

[Slide 9] And now let's go to the three key aspects of Parkinson's disease treatment: the first, medications, the second, therapies and the third, deep brain stimulation, and we'll discuss each of these in turn.

[Slide 10] Now some principles as it relates to Parkinson's disease medication. The Parkinson's disease medications that are available, are available to relieve or decrease Parkinson's disease symptoms and specifically the motor symptoms that we talked about earlier in this talk. Unfortunately, there are no medications yet available that protect the neurons in Parkinson's disease from degenerating and so we really are focused on the medications to help relieve symptoms. There's a lot

of research that is focused on medications that can protect neurons from degenerating and that, hopefully, is the future of Parkinson's disease.

So, the goal of the medication is to get the right dose while tolerating the medication as best as possible to improve and to maximize quality of life, and this may require ongoing adjustments of the medication to get the medication and the treatments to be as effective as possible. The responses to medication can vary from person to person and, therefore, combinations of medications may be necessary for the optimal result.

[Slide 11] The next few slides demonstrate all the medications that are available for treatment of the motor symptoms of Parkinson's disease. And I'm not going to go through each one; there're just too many to mention. I just want to give a sense of how many there are. And so, there are a lot of different options that you can try with your doctor if there are problems with the medications, you're on now.

Some brief points about the medications. The first category of medication here, dopamine precursors, are all medications that contain levodopa. Levodopa is the precursor to a brain chemical called dopamine, which is low or lost in somebody who has Parkinson's disease. So, the goal of many of these medications is to increase the dopamine in the brain. And one of the key ways to do this is to ingest levodopa by mouth typically, although there are other ways of getting levodopa into the system, and then the levodopa gets transferred into the blood through the gut wall. And then, from the blood, can actually enter the brain crossing the blood-brain barrier. Once it's in the brain, levodopa can be converted into dopamine. And so, introducing levodopa into the system, into the body is one of the key ways of treating Parkinson's disease and remains the most effective way of treating Parkinson's disease today.

Carbidopa-levodopa comes in many different varieties. Comes in the immediate release, which the brand name is Sinemet®. It comes in an extended-release form, one that's generic and another one called Rytary®. It comes in an orally disintegrating form; it comes in an intestinal gel, and it even comes in an inhalation powder.

[Slide 12] There are other medications that are available that enhance the effects of levodopa by, for example, decreasing its breakdown or by mimicking dopamine in the brain, and so all of these medications enhance the dopamine system in different ways.

[Slide 13] There's one medication that's available called istradefylline or Nourianz®. This is a medication that works on a different chemical in the brain. Works on a chemical called adenosine and it is unique in that it does not interfere or involve the dopamine system.

[Slide 14] Now as I mentioned earlier, there are motor symptoms with Parkinson's disease, but there're also non-motor symptoms of Parkinson's disease. And the non-motor symptoms of Parkinson's disease need a lot of attention and treatment as well. They sometimes and often are more problematic than the motor symptoms, especially as Parkinson's disease advances.

There are three medications available that are specifically indicated for Parkinson's disease. So, for example, pimavanserin is specifically indicated for psychosis that may develop in the setting of

Parkinson's disease. However, there are other strategies for dealing with non-motor symptoms and there are other strategies for dealing with non-motor symptoms that are not on this list, for example, for depression, for sleep disorders. There are many ways to address these symptoms without going to a medicine that has been specifically indicated for Parkinson's disease. So, the major point of this slide is to discuss with your doctor any non-motor symptoms that you may have, and there may be a Parkinson's disease-specific treatment that's specifically indicated for Parkinson's, but there may be other medications that your doctor suggests as well that may be very helpful to you. So, discuss all the non-motor symptoms so that you can get that treatment that may be appropriate for you.

[Slide 15] Some other key important things to know about the medication and that is for many people it is important to take the medication on time, as prescribed. Some people do not need the medication to be so carefully timed, but many people do. And so, if your doctor says to take it on a specific schedule, try to keep to that schedule as much as possible because missing a dose can greatly affect symptoms, especially later in the disease. So, people with Parkinson's may be advised to keep a diary to help follow symptoms, side effects, drug effectiveness and possible food interactions and that may help advise your healthcare professionals in when you should be taking your medication during the day. At this point, I want to point out that APDA has a free Symptom Tracker mobile app which is available on the App Store or Google Play. And this you can use on your phone or on your iPad to help track your symptoms during the day and can give you a sense of how you're doing when you have your conversations with your doctor.

[Slide 16] Let's now go to rehabilitative therapies as the second arm of treatments that are available for Parkinson's disease. It's very important to know that these therapies are available and can be accessed and very helpful to people with Parkinson's disease. First is physical therapy, and that is a therapy that helps improve balance, can help walking, can help build up strength and can be really important in Parkinson's disease treatment. The second is speech therapy and this can be very important for speech problems. I mentioned earlier that a soft voice can be problematic for people with Parkinson's as well as other speech difficulties. And then swallowing difficulties can develop as Parkinson's advances, and this too can be treated and addressed with speech therapy. Third is occupational therapy and this focuses on improving fine motor skills and cultivating independence and independent living.

I'm often asked, "When is a good time to start these therapies?" And, really, the answer is as soon as you can because there may be subtle changes in your walking, in your fine motor skills, in your ability to do your daily functioning, in your speech, that you may not have noticed but can be corrected and starting early is always good practice to get a handle on these subtle changes.

[Slide 17] We'll now discuss the third arm of treatment, which is deep brain stimulation (DBS), and this is a neurosurgical procedure in which electrodes or wires, are placed deep within the brain and it delivers electrical impulses to deep brain structures in order to improve Parkinson's symptoms. The electrodes are then connected by a wire, tunneled under the skin, and connected to what's called an implantable pulse generator or IPG in the chest. And this IPG can be programmed to deliver specific types of electricity to the brain. And it can be programmed using a remote device, a programmer.

Now this type of treatment is well studied. It's been done on hundreds of thousands of patients across the world for many decades. It's not a research protocol in any way, but it is not a procedure that is appropriate for every patient with Parkinson's disease. It is most appropriate for patients who find that their medications do not give a long-lasting effect and they have a lot of cycling during the day of medications working and not working and working again, what we call on and OFF time. And when you're in that type of situation where the medications do not give a nice robust long response, that's when deep brain stimulation should be considered and that's definitely something to bring up with your care team.

[Slide 18] So, let's talk a little bit about what a healthcare team means. What's important in Parkinson's disease is accessing the treatments that we discuss. We have medications, we have therapies, we have surgery, potential surgeries, but how do you know what to get when? And that's because you surround yourself with a good healthcare team that gives you advice on these various questions as they come up.

So, first we have the movement disorder specialist or the neurologist who knows about Parkinson's disease to help with diagnosis and medical management. Next, however, we have our rehabilitation team, our physical therapy, occupational therapy, and speech therapists. We can't forget about our general healthcare providers who can help with managing some of the non-motor symptoms that may be more in their wheelhouse than in the neurologist's wheelhouse. Maybe a urologist can help with urinary symptoms, a gastroenterologist may be able to help with gut symptoms; we want to involve those people as well. We have our wellness professionals who can help with ancillary movement type techniques that can help a person live their best life. And, of course, there's psychosocial support where psychiatrists, social workers and psychologists can help with mental health issues. **[Slide 19]** And, finally, we have community support, family, and American Parkinson Disease Association as your support team to help you get the best treatments available.

[Slide 20] Here is a slide that gives you some information about American Parkinson Disease Association. And we have a toll-free help line, 1-800-223-2732. We have a very robust website, and we are available on all social media outlets. So, find us and we can help connect you with programs and services in your area.

Rebecca Gilbert, MD, PhD

[Slide 21] On that note, I would like to pass the baton to Annette Kluge for her talk to continue our discussion on accessing the best treatments for Parkinson's disease. Annette, it's all yours.

Annette Kluge

Thank you. **[Slide 22]** So, today I get to talk to you about "Habilitation for Individuals with Parkinson's disease." **[Slide 23]** So, first of all, what is habilitation and why does Banner Neuro Wellness believe it's the solution to manage PD through the continuum? Let's start with the definition of habilitation. Habilitation refers to a process aimed at helping individuals with disabilities obtain, keep, or improve skills and function for daily living. And, of course, isn't that the goal?

So, what we did, was we attempted to look at what care is happening clinically and what families and individuals need. So, let's talk about that. **[Slide 24]** First, the challenge of the current medical system in the treatment of Parkinson's disease. Not all people with Parkinson's disease have a movement disorder neurologist in their community or they don't understand the benefit of having a movement disorder neurologist. Also, there's limitations if somebody doesn't drive or if the clinic is far away. Secondly, therapy services are for a prescribed issue and are limited in duration. So, when the goal of the therapy is achieved or the duration is over, their therapy services end. Also, what about mental issues? Not all practitioners are equipped to provide for social, emotional, and isolating effects of having a neurodegenerative disease.

[Slide 25] So, what does the family and the person with Parkinson's need? First, disease management. Individuals and families need to feel comfortable in managing the disease. Not only the physical limitations that may occur but also medication management. Ongoing disease-specific exercise and wellness programs need to be available to help individuals maintain skills that they obtain during formal therapy. Families and individuals with Parkinson's need a peer group that understands the challenges of Parkinson's disease. Resources for managing social and emotional issues must be readily available. And accommodations must be provided to help people stay safe from falls and free from hospitalizations in their home.

[Slide 26] So, Banner Neuro Wellness endeavors to bridge the gap in care through a community model for habilitative services. What can we do on a daily basis to provide for these needs and fill these gaps in care?

[Slide 27] Here's our team. I'm lucky enough to speak with you today. We also have therapists as part of our team. We have a physical therapist, a speech pathologist, a music therapist. We have a social worker. We have our team of exercise physiologists, we have community providers who help us with educational sessions, we have a planning committee for social events, and we have retreat services, which is actually nonmedical respite care.

[Slide 28] So, how do we fill the gap between neurologist visits? Well, we consider it that we need to have education to fill those gaps. First, we have an early intervention six-week program for people newly diagnosed with Parkinson's. And in each of those weeks, we discuss a different aspect of the disease and how to manage it. We also have local experts speak and in speaking engagements, we have coffee talk support groups and then we have peer discussion during our support groups so that people can share. And you know that you are the expert in your disease process so, that sharing is extremely valuable.

[Slide 29] What is the solution for limited therapeutic care? Our exercise physiologists at Banner Neuro Wellness offer a variety of classes to address symptoms of PD. Group exercise improves endurance, cardiovascular fitness, muscle strength, gait, and balance. Boxing address bradykinesia, proprioception, and kinesthetic awareness. Yoga addresses rigidity and balance. Dance addresses gait, balance and the use of the weight shifting to combat freezing. Our speech pathologist has a speaking group to address voice projection, articulation, and swallowing issues. Our neuro music therapist addresses memory, recall, voice, and the use of rhythm to stimulate ease of movement.

And, of course, we encourage our members to try all of these classes, see what they like, so that they're diligent in their exercise and wellness programs.

[Slide 30] How do we address social and emotional concerns? Support groups provide friendship, comradery, companionship through shared experience and practical solutions to common problems. Counseling at Banner Neuro Wellness addresses depression, anxiety, grief, interpersonal communication, isolation, and caregiver burnout. Social work services help to navigate disability benefits, transportation needs, long-term care planning and resources and referrals. And social events at Banner Neuro Wellness allows people to get together in a safe and loving environment and share and be a part of a community.

[Slide 31] And, of course, we want to provide services through our members' continuum. Our modified class structure allows individuals to continue regardless of ability or fall risk. The Banner Neuro Wellness physical therapists provide instruction on proper body mechanics to not only our members, but to their care partners. She provides skilled intervention, adaptive equipment, and home safety evaluations to decrease falls and injury. Our care partners groups help relieve stress and offer peer support. In-home respite care provides support to both our member and the care partner, so the care partner can get out and do some care for their own personal needs. And having the proper support and skills allows the individuals to stay home with their loved one through the continuum.

[Slide 32] So, let's talk about some of the successful outcomes of Banner Neuro Wellness. Individuals and families have a better understanding and feel more equipped to manage their PD. Through frequent and ongoing interactions at Banner Neuro Wellness, the team is able to identify any exacerbation of symptoms and advocate for prompt intervention. Individuals are able to maintain function and slow the symptoms. Through education and support, people feel that they can have self-empowerment and can advocate for each other. Through surveys like the PDQ-39 (Parkinson's Disease Questionnaire), we have found that through our interactions at Banner Neuro Wellness they have a higher quality of life. Peer support is readily available. Through our interventions, we have fewer falls. And through support groups and resources and respite care, we have a decrease in caregiver burnout.

[Slide 33] And if you Googled Banner Neuro Wellness, you would find these are some of our testimonials. And I invite you all to take a look and, also, to look for habilitation services in your area and advocate for habilitative services.

[Slide 34] And now I'd like to turn it over to Joanne.

Joanne Ruelas, LMSW

Hi there. Good morning to those who are in Arizona, and good afternoon to those who are listening in from the East Coast. I am Joanne Ruelas, the social worker and educator here at the Muhammad Ali Parkinson Center with Barrow Neurological Institute, and I am pleased to be a part of this presentation put on by the APDA.

I have no financial disclosures. **[Slide 35]** I wanted to also share with you all, many of my patients ask me, "Well what is it that a social worker does, particularly in my role?" And my response is, "It's a much shorter list to tell you what I don't do," because it's true. The social worker wears many different hats.

On the presentation slide, you will see that caring for your loved ones, there are many resources and benefits available. These are some of the specialty organizations. Ours, of course, is listed here. Please feel free to reach out to us to learn more about our support groups, our educational programs, and exercise programs that are currently being held virtual.

I certainly encourage you to look into support groups. I'm always talking to my patients and their families about making sure that they make a good support network, whether that's interpersonally with their friends and families or seeking support groups out there; and those are some of what we provide.

I myself run a couple of different support groups, and so, it's very beneficial and helpful to be involved with a group of individuals who are experiencing the same kind of experiences that you might also be running into. And then choosing one, I encourage you to attend at least three times to give them a chance because, I mean, each time you attend there's something different going on and none of each of the groups are the same. So, definitely finding one that would suit you best.

Also, I just want to thank all of the care partners that are in attendance today. Thank you for doing what you do. I know that it can be a tough job. And some of you may not view it as a job, but I mean it's definitely something that can wear on somebody; and so, I just want you to know that I appreciate what you're doing.

[Slide 36] So, another one of the services that I talk about a lot is Medicare. As you can see, you'll see who are eligible as well as the services that are covered. Some nonmedical care is definitely one that is often asked about, so that would include custodial care. Can my insurance pay for somebody to come in and help me take care of my husband, take care of my wife, take care of my loved one? And, unfortunately, that is not a benefit covered by Medicare. While it's been mentioned, there's nothing out there just yet.

Now what I have found recently is that some of my patients, they are able to receive, those that are eligible for home health services, for example, if they're receiving home health physical, occupational, and/or speech therapy, you can also include a CNA (certified nursing assistant) who could provide additional care such as assisting with showering and bathing. So, that is an option available and can be billed through Medicare.

And also, just as a PSA (public service announcement), open enrollment is currently happening. It started on October 15th and will end December 7th. It's definitely a good idea to review your Medicare selections and going back and seeing is the one that I selected a good option for me, or should I choose a new one that will cover my medications at a lower cost or even maybe some of the copays may have changed. And so, it's important to review that annually, of course.

[Slide 37] Social Security, that's a big one that I have questions on. A lot of what I talk to my patients and their families about is either they're coming up on retirement or maybe they have an extended period of time left before they're even ready to retire. What does that look like? Social Security offers a couple of different options. Many people are familiar with the Social Security retirement, which is, of course, something you've paid into throughout your working years; and you're eligible for upon retirement age. Determining what that age is you can always go to Social Security's website and figure out what age that is going to be as well as Social Security Disability. Now that's something that one would apply for, and somebody who is diagnosed with Parkinson's is eligible to receive Social Security Disability. So, applying for that and providing the information necessary that Social Security asks for to receive that benefit so that you can take advantage of it.

And then SSI, which would be Supplemental Security Income, that's just coming from a different pot of money. It is also the same as Social Security Disability. The only difference is that individuals who receive SSI have not paid into the benefit amount enough quarters of the year. So, you have to have up to, I believe it's 40, so that is ten years of work that you have paid into Social Security to be eligible for Social Security Disability. Otherwise, it would default on Supplemental Security Income, which is a lower amount that the benefit pays out.

Let me see here, another thing to consider in addition to also looking at come retirement time is also thinking about your insurance. This is something I talk to my patients and families all the time about is that making sure that you are covered insurance wise, whether that be that you're leaving an employer, are they going to provide continuous insurance through your short rolling into a long-term disability plan, through your employer. Is that an option or is COBRA (Consolidated Omnibus Budget Reconciliation Act) spending extra money to maintain the same insurance plan as you were on, is that an option for you? Or will you have to buy insurance through the marketplace? Lastly, Medicare is provided to somebody on Social Security Disability after they've been on it for two years, as I indicated on this slide here.

[Slide 38] In-home versus out-of-home care, that's another resource that I review a lot with my patients and their families. I mean there's certainly a lot to consider. What I have placed on the slide here are benefits and options available to the State of Arizona. ALTCS is the Arizona Long Term Care System through Medicaid through the State of Arizona, and so it is a state-funded program. You must qualify financially. There are, I'm going down my next slide. I do have additional resources that will review that. Hours in the home. So, the ALTCS, while it's not just for out-of-home placement, people can also utilize it to pay for caregivers in the home. However, the number of hours allotted to somebody receiving care in the home are decided based off of the case manager who is assigned to that patient. They determine how many hours they can receive.

So, say, for example, they come in, they do an assessment, and they say, "Oh, this person can receive 20 hours." So that 20 hours is divvied up between that one week of time, and so that is what's paid for out of the ALTC system. Thus, on the other end, somebody is in need of 24 hours care, they will not provide that much care in the home but rather recommend moving into a placement facility.

Same instance, private duty is out-of-pocket pay. You pay for a caregiver to come in the home. Placement agents can assist with finding an assisted living facility, group home, independent, and there's no cost for that service. However, they do make their money out of part of the first month's rent, if you will. The income that's paid to wherever the patient is placed at.

Those are all various levels of care. I strongly encourage you and I tell my patients and their families, "Please go to those facilities multiple times, not just during the designated tour time. Show up at different times during the day if you're able to take a look and see what kind of care is being provided there." Because, I mean, you are moving your loved one into a facility where they will live; and somebody won't be assisting to take care of them. So, I highly encourage that.

The Veteran's Pension Plan is another benefit for individual who are veterans. Please talk to, if you have a good contact at the VA (Veterans Affairs), I'm more than happy to review that in further detail. Sadly, it's not something that the VA advertises a lot, and they don't talk about that too much. However, knowing that it is a benefit is beneficial for sure.

[Slide 39] These other resources that I refer to in addition to the other resources that I talk to patients about, another one is advanced directives. You can obtain advanced directive forms at the Arizona Attorney General's website. I recently learned that through a bill called SB 1352, the State of Arizona is moving to an online platform where you used to be able to submit your advanced directive to the Arizona Secretary of State's website. Now it's moving to a platform called Health Current. Last time I looked, that registry is not live yet; but it will be. It requires a password, and then submission of the advanced directive. So, God forbid that something happens and then one is in the hospital, the physician can access because you're not going to be carrying around your advanced directives with you. They can access and see who would be the medical proxy to serve on one's behalf who is in the hospital.

Let me see here. I encourage you to look at the Pima Council on Aging to review the Arizona Long Term Care System. It is a great option for being able to view information, and they go over an overview of that very well.

And so that was it. That was the end of my presentation. Thank you so much.

Question & Answer

Rebecca Gilbert, MD, PhD

[Slide 40] Thank you so much, Annette and Joanne, for your very detailed and informative presentations today. So now we are going to turn to our Q&A session. So, before the operator gives instructions to cue yourselves for questions, I'd like to remind all of you that we have hundreds of people on the Web and on the phone. So, for everyone's benefit, please keep your questions general in nature, and we will provide an answer that is general in nature. For our telephone participants, your telephone line will be muted after you ask your question. So, operator, can you please give instructions to our telephone and Web participants so they can cue themselves to ask a question.

Operator

Thank you. For telephone participants who would like to ask a question, please press *1 on your telephone keypad. A confirmation tone will indicate your line is in the question queue. You may press # if you would like to remove your question from the queue. For those participants using speaker equipment, it may be necessary to pick up your handset before pressing the * key. For Web participants, please input your questions into the question-and-answer tab in the lower left-hand window on your screen to ask a question. One moment please while we poll for questions. Thank you.

Rebecca Gilbert, MD, PhD

All right, I think we're going to get started. I'll take our first question from the Web audience. This is a great question from Wayne, and this is probably a question for Annette. "Many of the activities and support groups that you talked about are done in groups or in a community, and that is proper. However, do you ever find it appropriate for Parkinson's patients to develop relationships through one-on-one contact visits in their home, something on the smaller side?"

Annette Kluge

Absolutely. We do that. It's so hard to get a full picture of what somebody is doing without seeing their home environment. So, we can't assess fall risk. We can teach people how to sit in a chair and how to navigate a hallway. But unless we know what you're dealing with in your home, we don't have the full picture.

So, we do have both our physical therapists and our social worker that will do home assessments and home counseling if needed to get a better idea of what somebody's dealing with on a more personal level.

Rebecca Gilbert, MD, PhD

Okay, fantastic. So, here's a question for Joanne. "In a lot of the programs that Annette was talking about seem like they may cost money. Are there insurance resources to pay for exercise classes and sort of ancillary services that may be very helpful to people with Parkinson's?"

Joanne Ruelas, LMSW

Rebecca, I get that question asked a lot. I don't believe that I'm not familiar with any that are out there for exercise; however, having insurance to pay for the physical/occupational therapy, at least at a minimum, that's an option. Just to put it out there, our center, we provide exercise classes remotely through virtual access; and our fee is $30 a month. So just, I mean I know that just kind of shopping around might be helpful to find something that is of a better cost nature.

Rebecca Gilbert, MD, PhD

Okay, great. There are a bunch of medical questions. I'll take one from Cynthia. And she asks, "Are there different types of DBS?" And so, the answer is that in Parkinson's disease, there are typically two main targets for Parkinson's disease symptoms, the subthalamic nucleus or a part of the brain, the GPi (globus pallidus internus), and that would be a discussion with the neurosurgeon which target is appropriate for you.

There are also three different manufacturers of deep brain stimulation equipment. It used to be there was one manufacturer. Now there are three, and they each have pros and cons. They each have subtle advantages, and some have disadvantages, so you really want to discuss those different options with the neurosurgeon. So, there really are different types, and they all pretty much have the same focus and the same goal. And mostly they lead to the same result, but there are some subtle differences that you want to talk with your neurosurgeon about.

Okay, so the next question would be a question for Annette. "I went to a support group, but I did not find that the people in the support group had similar symptoms to me. Is there a way to find a support group that's more compatible with my symptoms?"

Annette Kluge

I would recommend trying different support groups. Particularly like at our center, we have a coffee talk which is anybody who's dealing with Parkinson's. It could be the care partner. It could be the patient. It could be an adult child. That group may have more people dealing with particular things. We also have a women's group just for the gals, and we have a men's group. So, hopefully you have choices in your community, and I think it is important to find some place where you feel comfortable. Don't give up. Keep trying.

Rebecca Gilbert, MD, PhD

Okay, great, thank you. So, here's a question for Joanne. What are some care options if I really want to keep my spouse at home? And now you mentioned a lot of Arizona-specific resources. We have a comment in the comment box if you could maybe make statements that may be more applicable or applicable to people that don't live in Arizona.

Joanne Ruelas, LMSW

Sure, yes. So, let me see. So, definitely, I know that a lot of the private duty resources where you pay for care, a lot of those companies that exist here in Arizona, they are franchises, and so they exist throughout the United States. So, if you did a Google search for private duty, that would be the appropriate term for searching for a caregiver agency.

Now if finances are an issue I would certainly look to your state, their Medicaid site. And so, every state's, so, for instance, Arizona is the ALTCS and access system. So, in your state the Medicaid system definitely would have a different acronym. So, if you searched your state's Medicaid site to see if they had a long-term care option available, some people do have long-term care benefits; and so, you've paid into this program. It's time to use it.

And other options would include, like let's say your loved one only, not only, sorry, not to minimize, but if they just need somebody to come in and sit with them and maybe they just need somebody there to, you know, we have different companies. There are definitely volunteer agencies available, and so I would also search for your state, because like here we have the Area Agency on Aging, and so there are different versions of that throughout different states. So, like senior agencies or what the different state might call them. But certainly, getting plugged into that could lead to a multitude of additional resources available volunteer wise.

Rebecca Gilbert, MD, PhD

Great, thank you. So, we have a couple questions for Annette. So, could you maybe just review for our audience a discussion of where you work, where that is, and are there branches in other places? And if you don't have access to your specific center, how do you get a similar center in some other part of the country? So, a similar question to you that was posed about the financial resources to Joanne, a similar question to you. How do we make this more applicable to people outside of Arizona?

Annette Kluge

Well, I think my end slide is, I tried to sum it up. There are not a lot of centers like this. We are lucky to have in Gilbert, we have a sister facility in Sun City that does much the same things. But we've had people nationally come and look at our center to see what it looks like.

I think really what needs to happen is that you as individuals, as care partners, need to let APDA know. I know they've given us a lot of help; but this needs to be the form of care because it really does offer the best quality of life for both the person with Parkinson's disease and the family. So, advocate in your community. Tell your neurologist; get the word out there.

Rebecca Gilbert, MD, PhD

Okay, excellent. And just to add to that, certainly your center is very unique; but there are other movement disorder centers around the country you can access. Most major cities will have one, and you can start there. Not necessarily as robust as your offerings, but certainly has a lot of other resources in other parts of the country. So, thanks everyone for putting those comments into the chat.

So, we have a medical question here that I'll tackle, which is what is your feeling on CBD use for Parkinson's disease? CBD is a chemical that is purified from the marijuana plant, and it is used for a whole bunch of medicinal purposes and is one of the elements along which, with another compound called THC, to be the two compounds that are called medical marijuana. And there's been a lot of discussion and some research into whether CBD (cannabidiol) and THC (tetrahydrocannabinol), which are these components of medical marijuana, and their help in Parkinson's disease symptoms.

And so, just off the bat, chemicals that are purified from plants are often used as drugs in various contexts. That part of it is not unique, but there is a sort of politicizing of these particular compounds for a whole bunch of reasons. And so, trying to separate that politicization of these chemicals can be tricky.

And so, really what we need is data. We need data. Does this chemical help Parkinson's, and what symptom of Parkinson's does it help? And that data is hard to come by, but there have been some clinical trials and hopefully some clinical trials that are ongoing right now to try to see if this chemical helps the tremor of Parkinson's, for example, or insomnia in Parkinson's or a dystonia or a twisting feeling of Parkinson's. And we really need that data to be able to, just like any symptom and any compound, we need that data to be able to justify its use and to recommend its use, really.

And so right now we have just anecdotal data. Somebody goes to their medical marijuana facility. They try it and they tell us whether it helps or not. And that kind of data can be useful, but to really be impactful, you need a properly done clinical trial. So, as that data comes in, we can have a better understanding of how to use these chemicals and these medications for Parkinson's disease, and I hope that helps to adjust the questions.

We have another question that may be helpful for Annette to answer. I have difficulty getting out of my house. I can't drive, and I don't have anyone to drive me. Is it okay if I do physical or occupational therapy in my home as opposed to going to a facility to get that therapy? How do you balance those two things?

Annette Kluge

Absolutely. If you can get therapy in your home, do it. I think that one of the things that you might want to ask the physical therapist, or the occupational therapist is if they have experience working with somebody with Parkinson's disease. Not all of them do. So, if you can get the proper person, when you're calling your organization, ask specifically for a therapist that is familiar with Parkinson's; and definitely get that therapy in your home.

Rebecca Gilbert, MD, PhD

Perfect. Here's a question for Joanne, maybe Annette as well. I've heard the term "palliative care." What does that mean, do I need it, and how do I get it?

Joanne Ruelas, LMSW

That's a really good question too. And I failed to touch on that, because that's definitely something that I talk to a lot about as well, palliative versus hospice care. And I know that through the Parkinson's Foundation there is an initiative to be able to provide palliative care through the Centers of Excellence facility. So, like ours here at the Muhammad Ali Parkinson Center, that is what we are going to be striving to do. So, as far as accessing it, I know that is something that we will be implementing here through our center and then as well as other Centers of Excellences nationwide. But palliative care, typically, and I know this is specific to Arizona, so I'm not sure about other hospice agencies as I have looked at another state; I believe it was New Mexico, and their version of hospice/palliative care is different from Arizona. So, definitely asking to see what does your palliative care services look like. So, for here in Arizona, palliative care is just an added layer of protection where you have an additional service provider through an additional agency at no cost to you where a nurse will come to visit. I know that typically a social worker is involved. So, accessing it is either by self-referral or the physician's office can do a referral for you as well. But it is definitely a benefit to take advantage of, and it is very much different than hospice. And it's not a steppingstone to hospice. So, I know that that's a very common misconception that like, "Oh, my gosh, once I get on palliative care, that means hospice is next. That means my loved one is going to pass away soon."

So, no, that's not it at all. I mean getting as much additional help that you can, particularly if it's something that's a benefit to you through your Medicare, taking advantage of it would be very beneficial.

Closing Remarks

Rebecca Gilbert, MD, PhD

Fantastic. Amazingly, we have reached the end of our hour together.

[Slide 41] And so, we have been able to answer so many of your excellent questions, and I really apologize to all our participants who've submitted questions, and we can't get to them. And I do apologize, but I want to thank you very much Joanne and Annette for joining us today; and I really want to thank everyone for participating in today's telephone and Web education programs.

If you have a question that has not been answered, you can speak with somebody at APDA's Scientific and Medical Affairs Department by either visiting our website, apdaparkinson.org and submitting a question there or calling 1-800-223-2732, and we can answer your question that way as well.

[Slide 42] If you enjoyed today's webinar, we hope you consider supporting APDA with a donation because with your help, APDA can deliver more programs and services like this one which are needed now more than ever during these very challenging times.

[Slide 43] And I want to remind you to check out APDA's Symptom Tracker app, which is an app that helps you or your loved one track their symptoms. The Symptom Tracker is available in English and Spanish and can be downloaded from the Apple Store or Google Play.

[Slide 44] I also want to emphasize to everyone on the phone that we really do appreciate your feedback and comments. I want to make sure that you complete the program evaluation form. To join us in this fight against Parkinson's and to learn more about the support APDA provides across the country through our network of chapters and information on referral centers, as well as our National Research Grant Program and Centers for Advanced Research, please visit us at apdaparkinson.org.

We all agree that being informed about your disease and treatment options is the best way to empower yourself and take control of your care. Have a wonderful day.