



Transcript

Welcome and Introductions

Stephanie Paul

[Slide 1] Welcome everyone and thank you so much for joining us today. **[Slide 2]** My name is Stephanie Paul, and I am the Senior Vice President of Development and Marketing at the American Parkinson Disease Association or APDA for short.

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 Acadia Pharmaceuticals for funding this important program and acknowledge their continued appreciation for the critical need to provide education programs like this one to people impacted by Parkinson's disease.

APDA is the largest grassroots network dedicated to fighting Parkinson's disease and works tirelessly to assist the more than one million Americans with Parkinson's disease live the best life in the face of this chronic neurological disorder. Founded in 1961, APDA has raised and invested more than \$177 million to provide outstanding patient services and educational programs, elevate public awareness about the disease and support research designed to unlock the mysteries of Parkinson's that will ultimately put an end to this disease. APDA distinguishes itself as a national organization working one on one with the Parkinson's community to make each day better.

And now to our program. **[Slide 3]** We welcome two distinguished presenters today: first, Dr. Marie Saint-Hilaire, who is the Professor of Neurology, Medical Director for the Parkinson's disease and Movement Disorder program and Director of the APDA Center for Advanced Research at Boston University, Boston University Medical Center; and our second presenter, Dr. Alice Cronin-Golomb, Professor of Psychological and Brain Sciences and Director of the Vision and Cognition Laboratory at Boston University.

Today we are delighted to have Dr. Saint-Hilaire and Dr. Cronin-Golomb share with us an overview to help you better understand mental health in Parkinson's disease. After the presentation, we will open up the program for questions from both telephone and Web participants. We encourage everyone 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.

It is now my pleasure to introduce Dr. Cronin-Golomb.



Presentation

Alice Cronin-Golomb, PhD

[Slide 4] Hello everyone, I'm very happy to join you today, and I hope we have a good conversation.

[Slide 5] These are my financial disclosures.

[Slide 6] Today we're going to be describing some nonmotor symptoms of Parkinson's disease, specifically the ones that affect mental health. I'm mainly going to be discussing the nonpharmacological aspects of how to treat these symptoms, and then the presentation will be turned over to Dr. Saint-Hilaire, my colleague, who will discuss some of the pharmacological strategies.

[Slide 7] So why talk about mental health in Parkinson's? I think you all know that there are some problems associated with PD in the area of mental health, otherwise you wouldn't be here. So, let's back up a little bit and, first of all, try to figure out why mental health problems in PD even exist. We're going to be putting the spotlight on vision, that is seeing, along with visual hallucinations; thinking, which we also refer to as cognition; on feeling or mood and on sleep. After describing each problem, we're going to provide some ideas about how to address them.

[Slide 8] First let's introduce some of the nonmotor symptoms. These include sensory function, so first of all, the blunted sense of smell that many people with PD experience very early in the disease. There are also problems with vision, and in some people, that includes visual hallucinations. Besides sensory, we have changes in mood and that can include depression, anxiety and lack of motivation or apathy.

[Slide 9] Another of the nonmotor symptoms is change in cognition or thinking, and that can include a lot of different components. First of all, you might experience slow processing speed, that is as you're thinking about things, it just doesn't seem to go as fast as it used to; it takes a little longer to think things through. There might be some difficulties with organizing or planning, and we refer to that as executive function.

Working memory is another area that people sometimes have problems with, and that's keeping something in mind. An example of working memory would be keeping a telephone number in mind while you find a pen to write it down. Spatial problems are there as well, which might result in getting lost in familiar or unfamiliar surroundings.

Other nonmotor symptoms include sleep problems and fatigue; and under sleep, we would include insomnia and acting out dreams. And then there's daytime sleepiness which is rather common.

[Slide 10] So why should we be talking about these nonmotor symptoms? Well, everyone thinks Parkinson's disease is a motor disease, which, of course, it is. There's tremor, there's slow movement, there's rigidity, there's postural instability and in some people, there's also freezing of gait. So, most people who know Parkinson's know that.



The nonmotor symptoms though are really important too. First of all, they often begin long before the motor symptoms. Sometimes years before the motor symptoms. They can interact with the motor symptoms to make them worse. It's important to know that they don't usually respond to the usual Parkinson's medications. And they can result in poor quality of life.

[Slide 11] To understand these nonmotor symptoms, we have to understand how the disease progresses, where the pathology begins, how it progresses over time in the brain. Here in each picture, the left is the front of the brain and the right is the back of the brain, just in case you're not used to looking at brain pictures as I am. Many of us use the Parkinson's disease staging system developed by Dr. Braak (Heiko Braak, MD). These brain pictures are showing three groups of stages of PD.

If you look at the first brain on the left, you're going to see dark areas which are showing pathology there in the lower brain stem at the bottom and at the olfactory bulb in the front. All right, so the brain stem there on the brain on the left, you can see that it's dark. The other place here is the olfactory bulb, so that's responsible for your sense of smell. So very early in the disease process, there's pathology in those areas. This is before you know you have Parkinson's disease. You're not having motor problems as yet. People early in PD lose the sense of smell and they have problems such as constipation and other autonomic disorders, and that comes from these lower brain stem problems.

All right, I'm moving on now to the middle brain. So, the pathology is still in those areas, but now it's throughout the brain stem. You can see how the whole brain stem looks dark. We've still got the olfactory areas affected there. Now it's affecting sleep and mood and the pathology is reaching an area called the midbrain, the substantia nigra (SN), which produces dopamine. And when that area is affected, we first see the motor symptoms of PD, such as tremor and rigidity. That's when the person is diagnosed with the disease.

The brain on the right is in later stages when the pathology is now in the higher areas of the brain, the cortex, which is important for perception and thinking.

So, this is why Parkinson's disease causes nonmotor symptoms. It's affecting areas devoted to smell, to autonomic function, to sleep and mood all beginning possibly even before the diagnosis because the diagnosis is based on the motor symptoms and then it affects thinking later on.

Now that we know that there are nonmotor symptoms, let's go through a few of them starting with sensory abilities. I've already mentioned smell so let's talk about vision. **[Slide 12]** There could be changes in vision in PD, such as in contrast sensitivity, color discrimination, depth perception, and visual scanning. By contrast sensitivity, I've shown a couple of pictures here, you can see that it looks blurrier in the picture on the right than on the left. That means you don't have as much contrast. You're not as sensitive to contrast between an object and its background. That's fairly common in PD.

Color discrimination is usually characterized by people mixing up blues and greens. Depth perception is pretty clear what that means. Visual scanning means your ability to move your eyes around and take in the environment. Your eyes, like many other areas of the body, are affected by the motor problems of PD. These visual changes can affect your comfort in doing certain tasks.



You might also know that many people with PD have the occasional visual hallucination or more than occasional. And it's possible that people who have other vision problems, such as the ones I'm listing there like contrast sensitivity, may be more likely to have the hallucinations as well. That's a topic of research.

[Slide 13] Here's an example of a higher level visual spatial ability, the ability to rotate and match figures. If you rotate one of the figures on the top, is it identical to the one next to it? Same for the figures on the bottom. In the real world, if you saw a building from a different angle than the one you're most familiar with, would you know it was the same building? Now we're not talking about basic sensory abilities. Now we're talking about cognition, about thinking and orienting. **[Slide 14]** The problems with visual and spatial function make navigating the world more difficult, so these and other cognitive motor and sensory problems can affect driving and walking. It's important to understand them.

[Slide 15] Let's talk about another aspect of cognition or thinking, and that's multitasking. Many people think they can do two or more things at one time. And I am here to tell you that almost nobody can do two things as well as they can do one thing, even young people. Anybody walking and thinking may have some trouble with both. People with PD have even more difficulty because walking is no longer automatic. You have to pay attention as you walk and that pulls your attention away from thinking.

[Slide 16] So how do we fix this problem? The traditional approach is to avoid multitasking, focus just on your walking. And that's fine, it is all right for some people, but for a lot of people that's not really a real-world thing. We're always doing something as we're walking or we're trying to do two things at once. So, we might try attention training, enhancing attention so you can walk and do something else at the same time. How can you enhance attention? Well, there's research being done on this now, including developing attention training programs and some other things I'll be coming back to soon, including exercise and sleep.

[Slide 17] Let's move on now from thinking into mood, including depression and anxiety and lack of motivation or apathy. **[Slide 18]** Medications do really work well to help mood problems in many people with PD. But here's a question we get rather often. "I already take so many medications. Are there any other ways to help my mood without taking more?" And, happily, the answer is yes.

[Slide 19] Get active. How many of you have been told that by your doctor that it's for real? We can't say this enough. Get moving to the extent that you can. Do exercise to the extent that you can.

[Slide 20] Exercise can improve a whole range of nonmotor symptoms – mood, cognition, sleep – as well as the motor symptoms – balance, gait and rigidity. It's about the closest thing we have to a wonder drug.

[Slide 21] If you want to try some exercise movement programs, you might look at the APDA website for your state and region. I've put the website address up there, the link up there. We're based in Massachusetts and, for example, if we look at the Massachusetts chapter, we see that it lists classes right now in dance, boxing, yoga, exercise, tai chi and art and music. Really, there is something for everybody. If you try one and you don't like it, try another one. Not only do you get all the benefits of



exercise, but you also meet people like yourself who are trying out these programs. And the social aspect may be an important and enjoyable part of what you're doing there.

[Slide 22] So besides physical activity, you can try some kinds of psychotherapy to lift your mood. Cognitive behavioral therapy is one that's used a lot now. Working one on one with a psychologist or a social worker, you'll learn how to use real-life strategies to boost your mood and find fulfillment. You'll be taught to think flexibly, to regulate emotions, to approach difficult situations and to communicate and use effective interpersonal approaches.

[Slide 23] We've talked about a number of components here of nonmotor symptoms. Let's also talk about sleep. When we think about insomnia, we think about not being able to fall asleep. But many people with PD don't have trouble falling asleep. They have trouble staying asleep. They may wake up often in the middle of the night. They might act out their dreams. They may have daytime sleepiness. Sleep is fragmented in PD, that is, you can't get a straight night of sleep; you keep waking up. And if you don't get a good night's sleep, it affects your cognition and your mood.

[Slide 24] Here's some tips on how to sleep better. First of all, try to minimize naps during the day to consolidate your sleep. Minimize caffeine, especially in the afternoon and afterwards. Drink less water before you go to bed, so you don't have to get up. Here's an important one, don't go to bed until you're sleepy. It doesn't matter that you've always gone to bed at 10 o'clock; if you're not sleepy at 10 o'clock, don't go to bed at 10 o'clock. Likewise, if you can't fall asleep within 15 minutes of lying down, get out of bed. Do something boring and nonelectronic until you feel sleepy. Don't go on your screens. Read kind of a dull magazine article till you feel sleepy again and then go to bed. Exercise during the day because exercise is going to help you sleep. It also helps people to keep a consistent sleep and eating schedule from day to day. Good nutrition is also important. Cognitive behavioral therapy also works well for insomnia, as well as for mood in many people.

We've talked about sensory abilities, thinking, mood, and sleep, all of which contribute to your mental health. **[Slide 25]** The important thing to know is that your mental health is very important to your experience with the disease. Find what works for you to enjoy good mental health and good quality of life.

Thank you.

Stephanie Paul

Thank you, Dr. Cronin-Golomb, for this very informative presentation today. I would like to now turn the program over to Dr. Saint-Hilaire.



Presentation

Marie Saint-Hilaire, MD, FRCPC

[Slide 26] Thank you, Stephanie. I want also to thank all the patients who have participated in Dr. Cronin-Golomb's studies because a lot of what we discuss today is based on her research with our patients, and, hopefully, some of them are listening today.

Dr. Cronin-Golomb has done a wonderful review of cognitive issues in Parkinson's and of nonpharmacologic treatments. I am now going to discuss how the neurologist approaches and treats these symptoms in particular, and we'll talk about the pharmacologic treatments.

[Slide 27] So, these are my disclosures.

[Slide 28] All right, let's start with anxiety. When you have concerns about your mental health, it is important to discuss them with your provider. Some people are ashamed to report their symptoms as they fear they will be interpreted as a sign of weakness. But as Dr. Cronin-Golomb mentioned, all the symptoms we discuss are part of the Parkinson's and secondary to the changes in the chemistry and the brain function caused by the disease. For example, anxiety is very common in Parkinson's. It occurs in about 40% of people with the disease and can even precede the onset of the motor symptoms by years. It causes a feeling of nervousness, fear, intense worry, or even panic attacks.

[Slide 29] Some people notice that their level of anxiety fluctuates during the day, like the effect of their Parkinson's medications.

So, people who have been taking Sinemet® (levodopa-carbidopa) for a long time may notice that the benefit of the medication wears off before the next dose and the tremor and the slowness reappear. In some patients, that period that we call the off time can be associated either with anxiety or panic attacks, an inner tremor that is very bothersome or it can increase an already present anxiety. And it can cause rapid breathing, a feeling of inability to move that are very distressing. This is why sometimes noticing what triggers the anxiety episode is important when you plan to discuss this with your provider.

There are also two other phenomena that need to be distinguished from the anxiety. One is called akathisia and the other is restless leg syndrome. Akathisia can occur in the off periods, and it consists of a feeling of restlessness and an urgent need to move. And people with akathisia need to pace around. Restless leg syndrome is a condition that cause also an uncontrollable urge to move but is because there's an uncomfortable sensation in the legs like ants crawling up the legs. And it happens typically in the evening or at night when the person is sitting or lying down. And moving eases this uncomfortable feeling. So, your provider might have to differentiate these conditions to find the good treatment for you because the treatment may be a little bit different depending on the cause.

[Slide 30] So as we discussed, the first step to treat anxiety may be to optimize your Parkinson's disease medication. But if the anxiety is not fluctuating according to your medication and if it is affecting your activities and your ability to do what you enjoy, you may want to discuss medications with your doctor. The two big categories of medications that we use are benzodiazepines and SSRIs



or serotonin reuptake inhibitors. The benzodiazepines most often used are lorazepam and clonazepam, but there are others. They both can cause tiredness and sleepiness and they can also cause some dependence. So, we usually try to use them sparingly for occasional episodes of anxiety. But if you have anxiety that occurs daily and needs chronic treatment, then the provider might choose to start an SSRI. There are a couple of names here on the slide like sertraline or Zoloft®, paroxetine or Paxil®, but there are others like Cymbalta®, which is duloxetine, or citalopram, which is Celexa®. There's no data on what is the best medication to use for anxiety in PD. So, the decision may depend on what other meds you take or your other medical conditions or the medications your provider is most familiar with. The SSRIs are taken once a day and they can interact with selegiline and rasagiline, so people who are on these medications need to be watched more closely when they start the SSRIs.

[Slide 31] It is important to report the symptoms to the provider, and there are also lifestyle changes that can help like Dr. Cronin-Golomb mentioned. And some people they will prefer to start with the lifestyle changes before starting medications because they're already taking so many medications. So, as she mentioned, practicing good sleep hygiene, exercising regularly, limiting caffeine and alcohol, exercise, tai chi meditation, yoga, or seeing a therapist or social worker can be used first but can also be combined with the medications. So, taking medication should not prevent you from doing all these other activities.

[Slide 32] So, let's switch to depression. Depression often coexists with anxiety in Parkinson's. It consists of feeling of sadness or a loss of interest in activities for a period of at least a week. It can cause sleep problems, poor appetite, weight loss and decreased facial expression. However, we know that these last three symptoms are often part of the Parkinson's itself, so it may be difficult sometimes to diagnose depression in Parkinson's disease. So that's why depression is underrecognized by healthcare providers.

Another potential reason, as I mentioned, is that some people don't want to report that they are depressed. They see it as a sign of weakness or personal failure. But in Parkinson's disease, there are changes in the brain neurotransmitters that cause depression like a decrease in the neurotransmitter called serotonin. So, depression is clearly part of the disease and secondary to the changes in the brain. Depression can also precede the motor symptoms of Parkinson's by several years.

[Slide 33] Depression is treatable. There are several medications that are available. For anxiety, the SSRIs are the ones that are often used because anxiety and depression often coexist. But there are other medications like bupropion and venlafaxine. In addition, we know that exercise can help with mood, so it is an integral part of the approach. There's no study on what medication is best to treat depression in Parkinson's. It may depend also on the preference of the practitioner and the side-effect profile of the medications and how they may affect the patient.

[Slide 34] The patients and their families should be alert to mood changes, loss of interest in activities, change in sleep habits, it could be sleeping too much or too little, and report them to the doctor. So, the provider may refer you to a mental health professional as well as prescribe medication, but there are studies showing that cognitive behavioral therapy can be very helpful, like



Dr. Cronin-Golomb discussed. There's also a new type of therapy called strength perspective therapy where people focus on their strengths rather than on their weaknesses. So, instead of employing the traditional model which focused on their problems and the failures in people, the strength-based approach allows practitioners to acknowledge that every individual has a unique set of strengths and abilities it can rely on to overcome problems. And, finally, there are some studies suggesting that transcranial magnetic stimulation (TMS) may be helpful in treating depression in Parkinson. So, it is being studied for this indication.

[Slide 35] Apathy, like anxiety, can be associated with depression in Parkinson's or can occur independently be itself as an isolated symptom. So, it presents as a flat mood, indifference, lack of motivation to do nonroutine activities like going out or even routine activities even. It is often distressing to the family because the person is not participating in activities they used to enjoy, and this is causing social isolation. It is also affecting the health of the person because they do not want to participate in activities like exercise and therapies. And we know that participating in social activities is as important for PD as participating in exercise.

It may be very difficult to differentiate apathy from depression. Sometimes an evaluation by a neuropsychologist helps. In general, in apathy versus depression, there's no feeling of worthlessness, despair or sadness like there is in depression. **[Slides 36]** Apathy is very difficult to treat. At this point, there's no proven treatment for it. Some people suggest that a trial of donepezil or an antidepressant may be considered in certain cases. The provider must explain the condition the patient, the family and encourage the patient to participate in group exercise programs because some people may show no interest in going out or participating in exercise. But when they brought to the exercise class, they can still enjoy it.

[Slide 37] Hallucinations can be very disturbing to patients and can affect up to 60% of the population of people with Parkinson. Hallucinations are perceptions [that] are not real and occur when the person is awake. So, they are not to be confused with vivid dreams which can also occur in Parkinson's, but they occur when the person is asleep. So, hallucination is when the person is awake and they're usually visual but sometimes auditory or tactile. They are related to chronic use of anti-Parkinson's medications, but there are other medications that cause them, such as pain medications, medications for bladder, overactivity, or cold medications. So, usually they start with the person thinking there's an object is something else, like thinking a fire hydrant is a little person or a child, and then it progresses to see animals or people that are not there. And they can become very bothersome to the patient and the family because some people can develop delusions, which are fixed beliefs. For example, being convinced that their spouse is having an affair or that there is a family living in the basement. And the delusions often have a paranoid aspect.

The risk factors for developing hallucinations in addition to being on many medications are advancing age and disease, cognitive decline and having other medical conditions such as cerebrovascular disease. **[Slide 38]** So, when the hallucination starts suddenly out of the blue, we must always rule out an underlying medical condition such as infection, often a bladder infection. We also look if new medications have been started. And if there's no clear cause other than the Parkinson's, the provider will start to decrease medications starting with the medication that are the least important. But eventually, if a patient is only on levodopa-carbidopa, it may not be possible to decrease the levodopa



because then the person will have too much difficulties moving. That's why we have to add a medication specifically for the hallucinations.

There is only one medication approved by the FDA for hallucinations in Parkinson. It's a medication called pimavanserin or Nuplazid®. It's taken once a day in the morning, and it does not cause sleepiness. Another medication often used, although is not approved by the FDA for this indication, is quetiapine, and we start it at night because it makes people sleepy. So, for some people, that may be an advantage if they have insomnia. The third medication is clozapine. It has been shown to work well for hallucinations, but it is not used very often because you have to monitor the white blood count every two weeks. And there are other medications that may help, although they are not developed for hallucinations. These medications are medications we use for memory – rivastigmine, donepezil, and memantine.

[Slide 39] So, it takes a village to take care of a person with a chronic condition. In addition to the neurologist, preferably a movement disorder specialist (MDS), the person must have a good primary team to help with some of the other issues, such as constipation, urinary symptoms or infection. They must participate in exercise activities. They may need a counselor or therapist, and they must have access to physical, occupational, and speech therapists who are familiar with Parkinson's. And having a good social network is also very important for the mental health.

[Slides 40] Unmet needs in the care of Parkinson's include raising the awareness of the nonmotor symptoms of the disease not only in the patient and the family, but also for the healthcare providers. There are also not enough mental health providers that are familiar with the issues in Parkinson's or know how to address them, so we need to increase training for this group of providers.

[Slide 41] We must also expand programs that have been shown to help patients and their families, such as cognitive behavioral therapy, and strength perspective therapies. For example, the APDA has a program called the PRESS™ (Parkinson's Roadmap for Education and Support Services™) program, which is an eight-week facilitated group providing psychosocial support to patients in the early stages of the disease. We must also expand support to the care partners.

[Slide 42] So, I hope this review was helpful, and I thank you very much for your attention. And I thank the APDA for organizing this webinar that's a very important topic.

Stephanie Paul

Thank you, Dr. Saint-Hilaire. We appreciate the comprehensive information you have presented. And we're sure that our listeners have found the content that you and Dr. Cronin-Golomb have shared extremely helpful.



Question & Answer

Stephanie Paul

[Slide 43] It's now time for the Question & Answer session. Okay, we're going to start with a question for Dr. Saint-Hilaire, and the question comes from Meegan. And it is, "My therapist suggested that the anxiety and panic that I feel has to do with my PD. Is that true?"

Marie Saint-Hilaire, MD, FRCPC

Yes, I think your therapist is right. Anxiety and depression are very frequent in Parkinson's. [They] are part of a condition, we consider them one of the nonmotor symptoms. So, seeing a therapist is great, but you may benefit also from specific medications for these as the Parkinson's disease medications will not help those. So, the levodopa or the dopamine agonists or the rasagiline they help the motor symptoms, but you may need specific medications for the depression and the anxiety.

Stephanie Paul

Okay, thank you, Dr. Saint-Hilaire. We have a question for Dr. Cronin-Golomb, and that is coming from Joe. And the question is, "What role will mindfulness play in coping?"

Alice Cronin-Golomb, PhD

That's a very good question. Mindfulness has become very popular as a treatment in all sorts of conditions now. There's not terribly much research done it specifically in Parkinson's disease. It certainly does not seem to hurt anyone. It is one of many potential ways of doing relaxation and focusing, which I think is good for reducing all sorts of symptoms of the disease of the nonmotor symptoms as well as potentially the motor symptoms. I think people are becoming more interested in doing more research on it because of its general popularity. I think one thing that mindfulness has that some of the other treatments don't have is that it might potentially increase your ability to attend to things around you and, as I was talking about earlier, it would be great to increase attention so that you can walk and talk at the same time, or walk and think at the same time. So, I think it's out there, and I think people are becoming more interested in it.

Stephanie Paul

Terrific. Thank you, Dr. Cronin-Golomb. I believe we have a question from a caller if we could take the caller, please.

Operator

Our first call is from Kathryn from Michigan. Kathryn, please state your question. Your line is now live.



Kathryn from Michigan

Thank you. I just want to know from either doctor, what book would be very good for a therapist to read who's working with a person with Parkinson's? I do a lot of the big brain things, mindfulness, relaxation, and things like that, but are there any books that they can recommend for a therapist?

Marie Saint-Hilaire, MD, FRCPC

I don't know personally of a book that reviews all these treatments in Parkinson's. That's a need. It's a real need. I know of a book written by Dr. Joseph Friedman about all the symptoms that patients report. So, it's more information for a mental health provider about the extent of all the symptoms that patients need. But I'm not aware of any good book reviewing other treatment of these issues in Parkinson's. I don't know. Alice, do you know?

Alice Cronin-Golomb, PhD

No, I don't. I would suggest that one thing they might do is take a look at a couple of the websites, APDA being one; possibly NINDS, which is part of the National Institutes of Health (NIH) because they have a large section about Parkinson's disease. They may find some information of interest there. I'm not sure how often the NINDS site is updated, but I've found it very useful in the past in taking a look at that. And that's the National Institute of Neurological Disorders and Stroke, which is part of the National Institutes of Health.

Stephanie Paul

Okay, we have a question. I believe Dr. Cronin-Golomb can answer this one. It comes from Brian, and the question is, "How much activity/exercise has shown to be effective?"

Alice Cronin-Golomb, PhD

That's a great question. It's the same question that everyone asks about exercise not just for Parkinson's disease. I'm sure that this is not sure for Brian, but for many people the question really is how little can I get by with and still get the benefits of it? We're all very busy, right, so there isn't really a single answer to that, unfortunately. There have been many studies of exercise and PD, and one of the variables in the studies is how much exercise? What dosage is going to work? And there's just tremendous variability from person to person. One person can get by with doing something once or twice a week. Somebody else might need a little more regularly. And part of the reason is that, first of all, the disease is different from person to person, but the symptoms that you're trying to treat through the exercise may differ from person to person. So, for one person it might be rigidity or a gait problem. For somebody else, they just feel that exercise clears their head. For somebody else, it's for their mood.

So, I would suggest that you start out doing what you can and build up as you go on. You can work with somebody at a gym or whatever kind of support group you might have there and increase it until you feel the effects yourself and see how much you can tolerate.



Stephanie Paul

Okay, thank you. Here's a question for Dr. Saint-Hilaire. This comes from Debra. What could be done for sleep issues that include waking up several times during the night?

Marie Saint-Hilaire, MD, FRCPC

That's a good question. It's a very frequent issue. A lot of people with Parkinson's have this interrupted sleep. So, first there is find out why you're waking up during the night. It can depend for the person. Some people wake up because they have to go to the bathroom. In that case, you have to address the problem with the urologist. You might need medication because you have an overactive bladder. And other patients it's because the tremor from the Parkinson's wakes them up. So maybe they need a long-acting form of levodopa at bedtime because the tremor is affecting them. Other people it could be very vivid dreams, and they wake up because they scream or they're thrashing around. There is treatment for that also.

Sometimes people just have just interrupted sleep because they have very poor sleep efficiency. In that case, practicing the good sleep hygiene, not having alcohol before going to bed, not looking at screens, TV or iPad or computer, for an hour before going to bed. And then there are certain medications that can help with sleep efficiency. So, there are several. I can name a few. One is gabapentin, one is trazodone. Usually we don't like to put people on chronic sleep medicine, but sometimes if it's a way for them to get some good night's sleep because it's very important. Otherwise they're tired during the day. Some people take the sleeping pill only once in a while not every night because you can develop a tolerance, but if you want to take it once in a while, a few times a week just to assure that some nights you have good sleep, it's also a possibility.

Stephanie Paul

Okay, thank you. Dr. Saint-Hilaire, here's another question for you. This comes from Naomi, and the question was, "I was diagnosed with PD last year. I find my depression is now severe. Someone mentioned transcranial magnetic stimulation (TMS) and that it has worked wonders for their depression, but I read that TMS doesn't work for PD patients with depression. Is that true?"

Marie Saint-Hilaire, MD, FRCPC

That's an interesting question because there are some studies showing that TMS, the transcranial magnetic stimulation, can be helpful in Parkinson, can be sometimes as helpful as taking a medication. So, it is worth taking it. Especially if you don't want to take medication or you have side effects from medication or it's not working, I think it is worth trying it. It is fairly benign. So as far as I know, the latest big analysis of TMS were pretty positive in Parkinson.

Stephanie Paul

Okay, thank you. Here is a question for Dr. Cronin-Golomb. The question is coming from Sarah, and it is, "My emotions have been all over the map since I was diagnosed. Is there a normal amount of time it takes for people to recover emotionally from this news?"



Alice Cronin-Golomb, PhD

I'm sorry that every answer I give is it depends on the person, but it's really true. So, there are probably a couple of different things going on here, especially if you're newly diagnosed. And one is that your experiencing a reaction to the news about your diagnosis, so we would call that reactive mood change. And that is something that shouldn't last terribly long. The other part of it is what we call endogenous, and that is part of the disease itself. So, depression and anxiety are part of Parkinson's. The parts of the brain devoted to mood are affected by the pathology of Parkinson's, so that's something that's going to go along with the disease. That's not going to lift necessarily by itself. But as both Dr. Saint-Hilaire and I have discussed, there are a number of ways of taking that on through medications or through exercise or through cognitive behavioral therapy, mindfulness. There are a lot of different ways of trying to get at that. So, don't give up just because it seems to be going on for a while. And don't ignore it. Try to get some treatment for it.

Stephanie Paul

That's terrific advice, thank you. This is a question for Dr. Saint-Hilaire. This comes from Julie, and the question is, "My husband has developed some serious short-term memory and cognition issues. Recently these have gotten worse. He uses the Exelon® Patch (rivastigmine transdermal system) but it doesn't seem to make much difference. Is there anything else we could try that might be helpful?"

Marie Saint-Hilaire, MD, FRCPC

That's a very good question. Unfortunately, the treatments we have, the medical treatments, the medications we have for memory loss in Parkinson's, like memory loss in Alzheimer's the same problem, is that our treatments are not very effective, unfortunately. So, pushing the dose of Exelon as high as he can go can, if tolerated, to the maximal dose; adding another medication called Namenda® or memantine may help a little bit. Another thing is also look at all the other medication he's taking. Certain medications for tremors, certain medications for dyskinesias, cold medication, bladder medication can affect the memory. So, it's a good opportunity, maybe you see somebody's who's a neurologist or geriatrician, to look at all the medications and reevaluate which one could also affect the memory. Also, we talk a lot about Parkinson's causing memory issues or depression, but don't forget there are also other medical issues underlying that could be taken care of. Like be sure his thyroid is functioning well, that he doesn't have any vitamin deficiencies. So, a good evaluation by the primary care to be sure nothing else is going on may also help.

Stephanie Paul

Thank you, Dr. Saint-Hilaire. Here's another question for Dr. Cronin-Golomb. This comes from Albert, and the question is, "That I have depression is a norm for me. Why do I feel worthless and what should I do?"



Alice Cronin-Golomb, PhD

Yes, it's a real difficulty for a lot of people. As we've been discussing, depression is so common. And part of what you want to do is see your neurologist or your geriatrician to see what kind of treatments might be available to help lift that depression. Those can be pharmacological. But then also, as we've been discussing, watching your nutrition, watching anything else you're ingesting like alcohol, getting exercise, getting sleep. Whenever one of those is off, it's really affecting the whole system. So, it's difficult to treat one of these in isolation. You kind of have to go after the whole problem. So, making sure that your sleep is good because otherwise your depression is going to not lift even if you have medications let's say. So, certainly start there, but it's also very important that you have social support, that you're doing the activities you enjoy.

As Dr. Saint-Hilaire was talking about, with apathy, one of the concerns of family members is when someone stops going out and they stop doing things that they used to enjoy. And you may feel that your depression is getting in the way of you doing that, but it's good to try anyway. It's good to involve yourself to the extent that you're able to. These things tend to be cyclical, and so if you're able to pull yourself out a little bit, that may give you a little energy, a little more ability to enjoy it; that will make you want to do it more. So, it's important to not just sit with the depression and not do anything about it.

Stephanie Paul

Okay, thank you. This question is for Dr. Saint-Hilaire. Comes from Kimberly. And the question is, "Does everyone with Parkinson's get dementia?"

Marie Saint-Hilaire, MD, FRCPC

That's an important question. If you look at a cross-section of people who have Parkinson, about 30% of people have dementia. But as the disease progress and as people get in advanced stages of the disease, experts think about 80% of people have dementia. And there are certain risk factors. So, advanced age and having more the kind of rigid form of the disease and being male are all risk factors to get the dementia.

Stephanie Paul

Okay, thank you. The next question I will actually leave for either one of you to answer. And this question comes from Rob, and it is, "Do you recommend any homeopathic medications such as ginseng, green tea, etc., for improvement of mental health?"

Alice Cronin-Golomb, PhD

You want to start, of course.



Marie Saint-Hilaire, MD, FRCPC

Yes, I'll start. I'll give the neurological answer. The neurological answer is that there is no proof that any of these supplements work to help memory in Parkinson's. So, I do not recommend any of them to my patients. The only one I recommend is vitamin D because a lot of people are deficient. But I don't think they can hurt, but before starting a supplement just check with your doctor or your neurologist because certain supplements can interfere with medication or can have by themselves some side effects. So, I'm not against them, but I'm not aware that any of them have been proven to help.

Alice Cronin-Golomb, PhD

I'd like to add to that. I agree with everything that Dr. Saint-Hilaire said, but other things about supplements is that you don't actually know what you're getting in them depending on the source. And the dosage, for example, can be really different from one to the next. So, that makes me a little leery of recommending them. I see nothing wrong with green tea, and especially if you find it relaxing, that's part of your process for relaxing, I'd say, absolutely, go ahead and do that. Some of the supplements though I would feel a little worried about if I was unsure of what was actually in them.

Stephanie Paul

Okay, thank you for that. This is a question for Dr. Saint-Hilaire. It comes from Roy, and the question is, "Does DBS or deep brain stimulation change mental state?"

Marie Saint-Hilaire, MD, FRCPC

That's a really important question. There are some reports that people after they have DBS could have more depression. That is why when people are screened for DBS, we screen them for depression and anxiety. And if they are felt to be significantly depressed or anxious, we recommend treatment before the DBS. But it's something to be very aware of. It's not a contraindication, but you need to be treated and followed closely for it. The DBS itself will not treat cognitive issues, will not treat depression, will not treat anxiety. The DBS treats only the motor symptoms.

Stephanie Paul

Okay, thank you, Dr. Saint-Hilaire. We have a question for Dr. Cronin-Golomb, and that question is coming from Marianne. And she asks, "How much of mood is related to dopamine deficiency versus one's attitude about having Parkinson's, that is, how much is biological versus psychological?"

Alice Cronin-Golomb, PhD

Right. And that's a really good question, and it's difficult sometimes to tease them out. I mentioned a little earlier that there's reactive mood change, reactive depression, which is when you find out that you have this disease and everything that goes along with that. So, just as you had received diagnosis of any one of a number of conditions, you might be anxious and depressed about that. But a part of it really is part of the disease. It's an endogenous depression and anxiety, and that's why



we've been saying that it's important to get that treated. That's something that's not going to go away as you don't have the reaction against it anymore.

The way you think about your disease, of course, that's going to affect how you feel. If you maintain a positive attitude to the extent that you can in a realistic way, I think that will really help you go far. Maintain your relationships with your family and your friends, and your social group. All of that is part of a positive orientation to it and there's no downside to that at all.

Stephanie Paul

Okay, thank you. This next question I'll leave for either one of you to answer, or both. It comes from Fiona. "What are some nonpharmaceutical interventions for restless leg?"

Marie Saint-Hilaire, MD, FRCPC

I am not aware of any nonpharmacological interventions for restless legs. I mean other than exercise. I mean be sure you're not iron deficient because if you're iron deficient, it can cause restless leg, so some people need to be on iron supplements. But other than that, I'm not aware of other vitamins or supplements that could help restless legs.

Alice Cronin-Golomb, PhD

No. I was thinking exercise might help because it helps with other motor symptoms, but I don't know the others.

Stephanie Paul

Okay, thank you. So, I'm going to take one final question for Dr. Saint-Hilaire, and the question comes from Richard. And he asks, "Are there concerns for drug interactions between antidepressants and Parkinson's disease treatments?"

Marie Saint-Hilaire, MD, FRCPC

Yes, good question. And this comes up pretty often. When we start SSRIs but other antidepressants also with people who have depression or anxiety, they can interfere with a class of medications we call MAO-B (monoamine oxidase B) inhibitors. So, these are selegiline and rasagiline. So, it's not a complete contraindication. So, it doesn't mean you cannot be on both of these types of medications, but it means that your physician has to be very careful when he puts you on the antidepressant. Be sure you don't have any side effects. You have to probably start with a smaller dose and you have to be monitored closely.

What it can cause sometimes with the rasagiline and selegiline—it's very, very rare—that sometimes people have something we call serotonin syndrome where you would become very tremulous and have your muscle jumping and get very sweaty and confused. So, to discuss with your doctor and you should know about if you present with these symptoms to contact your doctor right away.



Closing Remarks

Stephanie Paul

[Slide 44] Thank you so much, Dr. Saint-Hilaire and Dr. Cronin-Golomb. And my thanks to everyone for participating in today's telephone and Web education program. I do apologize that we couldn't get to all of the wonderful questions. **[Slide 45]** But if you do have a question or would like to speak with someone from our Scientific and Medical Affairs Department, I encourage you to visit our website at apdaparkinson.org or call 1-800-223-2732 and you can ask your questions there.

I also want to emphasize to everyone on the phone that we really do appreciate your feedback and comments and want to make sure that you complete the program evaluation form.

APDA is proud to support those living with Parkinson's disease by helping them live life to the fullest every day. We do this each year by providing more than 1,700 support groups that serve more than 75,000 people with Parkinson's Disease and their family members and to running 770 plus exercise groups attended by more than 21,000 participants each year. These programs help improve the symptoms of Parkinson's and lessen the impact of the disease.

We also offer educational symposia across the country on living well with the disease. These programs have been attended annually by more than 5,500 people impacted by Parkinson's. We rely on the support of the entire Parkinson's community to accomplish all of this.

To join us in this fight against Parkinson's and learn about the support APDA provides across the country through our network of chapters and information and 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.