

## Parkinson's Disease Diagnosis in the Young

Webcast

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Ted Cahalane

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### **Introduction**

#### **Andrew Schorr:**

Hello, and thank you for joining us once again for our Ask the Experts program brought to you by Patient Power and produced with Oregon Health and Science University every two weeks connecting you with an important medical health topic and leading experts from OHSU.

Just two weeks ago we spoke about Parkinson's disease, a serious movement disorder, and we talked about why should people with Parkinson's disease exercise. Well, now we have another aspect of Parkinson's and that is Parkinson's disease diagnosis and treatment for the young.

When we say "young" what do we mean? Most people who are diagnosed with Parkinson's, we're talking about a million and a half people in the United States, are in their 60s. Maybe the average age is about 64. But what if you're in your 40s or 30s, and there are some children too, but what if you're in your 40s or 30s and you start to have a little tremor, a little weakness, or maybe even a little trouble in your gait? What about that?

Now often neither the patient nor their doctor would imagine it's Parkinson's, but it certainly can be, and it can be quite a journey to get to an accurate diagnosis and then hopefully ultimately connect with a Parkinson's specialists, and we're going to meet people at the Oregon Health and Science University Parkinson's Center in just a minute, a leading neurologist there, but first I want you to meet a patient, someone who had this journey and is still on it, and that's Ted Cahalane who joins us from Anchorage, Alaska.

### **Ted's Story**

#### **Andrew Schorr:**

Ted is 50 years old now, but when he was 43 he had those symptoms, and he had a little problem in his right thumb and a little sensitivity in his forearm. Ted, tell us about what you were feeling back when you were 43. What were these symptoms, and what did you do about it?

**Ted:**

It started I guess when I was 43, I think it was March of 2003, I had a sensation in my right forearm. It just kind of felt tense all the time, and then shortly after that my right thumb began to twitch uncontrollably, not real noticeable at first, and it became continuous. It wasn't until about nine months later that my wife finally convinced me to go see a doctor about it. I just saw my general doctor, and he said basically that any time you have a tremor in a young person it's not good; it needs to be looked at; and he sent me to a neurologist in Anchorage, and that neurologist had me take some test and did lab work. I came back and got the results from that, and he said he thought I also had Parkinson's but that I should be going to a specialist someplace, and he recommended me to go down to the Oregon Health and Science University, and that's where I met Dr. Brodsky.

**Andrew Schorr:**

We're going to meet Dr. Brodsky, your doctor, in a minute. We might mention why did he say OHSU? Well the Parkinson's Center of Oregon at OHSU is a renowned center not just in the Pacific Northwest but in the whole country if not the world. They have lots of research going on and many programs to help people no matter what age they are with Parkinson's. Later on we'll mention about a symposium they're having for younger people, families touched with Parkinson's, that's coming up in just two days, September 19, 2008, at OHSU. I'll give you the details in just a minute.

Ted, so you are an oil engineer. You have three kids, three girls, a 15-year-old and two 13-year-old twins, that's a handful, and you work every day. So you went to OHSU, but the point is you're still living a pretty full life even though you have this chronic illness, right?

**Ted:**

Yes, I am. I really don't see myself in day-to-day life being handicapped too much. The biggest issue probably is what it does to my sleep. It's tough to get to sleep. If I wake up for any reason in the middle of the night my arm will start shaking, and it's difficult to get back to sleep, and that's probably the biggest inconvenience that it's caused me so far.

**Andrew Schorr:**

Now the other thing that we should understand too is that you've always been a cyclist. So you still get to ride your bike and in long-distance races. You're still doing that, maybe not as fast, but you're still doing that.

**Ted:**

Certainly not as fast. I don't know how much of that is Parkinson's and how much of that is turning 50 years old, but yes, I still am very active and can do physically almost as much as I have in the past.

**Andrew Schorr:**

All right. Well let's meet your doctor, and that is Dr. Matthew Brodsky, and he is an assistant professor of neurology at OHSU and treats people like Ted who are diagnosed with Parkinson's.

Dr. Brodsky, here we have not somebody in their 60s or 70s who may have a shorter lifespan but hopefully will live a long time like my dad who lived to be in his 90s and was active. Everybody wants to live to be 100 and live a full life, but certainly if you're diagnosed in your 40s or 30s with a chronic progressive condition it would seem like you would have to plot out your plan. So tell us about how you first of all confirmed the diagnosis of Parkinson's and then begin a discussion for that individual on what might be step one, step two, step three.

**Dr. Brodsky:**

Sure. When I first met Ted it was to make a diagnosis or in this case to confirm a diagnosis, which is often what we're doing as a tertiary care center of Parkinson's disease, it remains a clinical diagnosis. So if one has a history and then finds on exam of the cardinal, what we call the cardinal features of Parkinson's disease; a resting tremor, slowed movement, and muscle rigidity that tends to be more on one side of the body; that is sufficient to make a clinical diagnosis of Parkinson's disease. We do not yet have a blood test, a spinal fluid test, or an imaging test that can confirm Parkinson's disease. This is an important area of research for the future in trying to come up with earlier detection, but to date it remains a clinical diagnosis.

I'd say that Parkinson's disease is a bit of a misnomer. I think many experts now would agree that it's a syndrome that has these features in common and also that responds to certain classes of medications such as dopaminergic medications, but the causes are quite varied from person to person, and that's what we've been learning.

The second part of your question, when you've got someone who's younger who presents with Parkinson's disease you just have to take much greater care determining what treatments if any you're going to choose to use in those early years; five, ten, fifteen years; in these initial stages of Parkinson's because the consequences of starting for example a more potent medication may be greater and may be different rather than starting a different class of medication. Whereas when someone is in their, let's say, 70s and they're just developing symptoms there is less of a concern 10 or 20 years down the road of the same kinds of consequences than in someone who faces another 40 or 50 years in their life where these may become more disabling to them.

**Andrew Schorr:**

So it's not at all a once-size-fits-all treatment.

**Dr. Brodsky:**

Absolutely not. We really try to tailor our treatment plan with each individual.

**Andrew Schorr:**

All right, now let's understand this a little more. So first I want to go back. Would different people present as you doctors say in different ways? In other words some people might have a slight tremor. Some people might have a gait issue.

**Dr. Brodsky:**

Right.

**Andrew Schorr:**

How could it look different in different people?

**Dr. Brodsky:**

As you mentioned, many people with Parkinson's disease have a resting tremor, although not everyone, and there are some folks who have what we would diagnose as Parkinson's disease who have no detectable rest tremor, but they really fall in the minority. Those who have a predominance of tremor who have a lot of tremor and not much in the way of other signs, just slight signs of slowed movement and rigidity, actually tend to do better in the long term. The progression of their Parkinson's tends to be slower than those who present, for example, with a greater degree of muscle rigidity or balance impairment.

What's often referred to as sort of a fourth cardinal feature of Parkinson's, which is postural instability and impairment of gait and balance, usually comes about later in the course of Parkinson's and is usually not an early feature. That brings up another point that it's important to try to distinguish what we call idiopathic Parkinson's disease or typical Parkinson's disease from one of the atypical parkinsonian syndromes. So there are a host of other rarer neurodegenerative conditions that tend to progress more rapidly, tend to cause more in the way of cognitive impairment, postural instability early on, that are not typical Parkinson's disease.

We try to distinguish that because, well number one the prognosis really is different, and we try to counsel people in that regard, and also the treatment options become more limited in those atypical syndromes.

**Andrew Schorr:**

It seems like then if there are subtypes, if you will, in that it's less common anyway in a younger person that someone like Ted, even from a distance like Alaska, to consult with a Parkinson's specialist at a Parkinson's Center such as you have at OHSU that that's worth the consultation to help understand what are you dealing with.

**Dr. Brodsky:**

Yes. I would say at the very least a thorough consultation with someone who this is their focus and their specialty really is worth it. The followup care by let's say a general neurologist certainly is appropriate. Especially if someone's living at quite a distance it becomes an inconvenience, and if there's a good relationship between a local doctor and a specialist a lot of which can be potentially handled via telephone calls and e-mails, that's certainly feasible, but I think at least a one-time consult, and often what we do at our center is a typical situation will be an initial consult, certainly gets local followup but periodically they'll come back to our center for reevaluations but maybe less frequently than they would see their local neurologist.

In other situations we have someone come on a more regular basis just to see us. So it really depends on one's availability, resources, etc.

**Andrew Schorr:**

Ted, so you're glad you made the trip, and you make it every so often for consultation with Dr. Brodsky, right?

**Ted:**

Currently I go down once a year. When I first started I think I might have made it down three times in one year, but then quickly went to like every six months or so, and now once a year seems to be fine.

**Andrew Schorr:**

But you're glad that you got sort of the workup at OHSU?

**Ted:**

Oh certainly, yes. I'm glad I had gone down there. That's true.

**Andrew Schorr:**

So let's go through this. Tell me what medications you're taking now and how often.

**Ted:**

Like I said, four times a day and the two medicines are Artane, which is predominately to treat the symptom of the tremor, and then the Mirapex which is, well I guess I should have Dr. Brodsky say what they're for I guess. Do you want to follow up on that?

## **Treatment Options and Strategies**

**Andrew Schorr:**

I'll ask Dr. Brodsky. Dr. Brodsky, more broadly, and we'll understand Ted's situation, do you have a lot of tools available to you when someone like Ted then in fact does need treatment?

**Dr. Brodsky:**

Yes. In the younger patient but someone who is at a point where they want some improvement in their mobility, again this is debated, some practitioners, even Parkinson's experts, would start some symptomatic therapy regardless of whether a patient thought that they felt disabled or not; but certainly once someone feels like they're at a point where they want some kind of change, if the tremor is disabling or the slowed movements are a problem, we'll start one therapy or another.

We should note that in many cases it's actually the slowed movements that people have that are a really impairing feature of Parkinson's early on and not a tremor. That's because typically a tremor goes away when one starts using their hands to do things for example.

In Ted's case though, the Artane, the trihexyphenidyl, is a medication that can help suppress tremor. It's actually a medication I tend to not use very often for Parkinson's disease except in rare cases where someone has a tremor-predominant form and in younger patients, and in that case it can help suppress tremor when tremor is more severe.

The pramipexole, or Mirapex the brand name, is a dopamine agonist, and that is effective somewhat for tremor but also to help improve slowness of movement, slowness of mobility, and while it's not as potent as a medication called Sinemet or levodopa, we try to avoid the more potent medications in younger patients because of potential complications that can arise when you pick that as your first drug to use.

**Andrew Schorr:**

We're going to talk a lot more about treatment as we continue. We have a lot more on our webcast. We've got Dr. Matthew Brodsky, a neurologist and a specialist in Parkinson's with us from OHSU. If you're a younger person, and I like to think the 30s and 40s as younger, after all I'm in my late 50s so it sounds young to me, you can ask a question also of Ted Cahalane who has been living with this now for about seven years, and he's joining us from Anchorage, Alaska. This is what we do on Ask the Experts brought to you by Patient Power. We invite your questions for our live webcast as we discuss Parkinson's in the younger patient. We'll be right back.

Welcome back to our live webcast. Andrew Schorr here happy to bring you this Ask the Experts live webcast. We invite your questions, and we'll be posing some to Dr. Brodsky as we continue our program, and I'm happy to pose some to Ted too who after all has been living with it but still cycling and being an oil engineer up in Anchorage, Alaska, and working every day yet taking medicines and understanding that it is a progressive condition and so working with Dr. Brodsky and really have a long-term plan of how to stay ahead of the Parkinson's, and also we always keep our fingers crossed, I know I do in my leukemia, for a cure in whatever your health concern may be.

**Andrew Schorr:**

I just want to go back to Ted for a second. Ted, so we're kind of a-matter-of-fact about this whole thing, but when someone is diagnosed with Parkinson's, and certainly if it comes out of left field and you're in the prime of life, it's a blow, and I'm sure to your wife and your kids said, Huh? What's going on, and probably nobody knew anything about it.

How did you cope and how have you kind of adjusted to this living with your family now since then?

**Ted:**

Yes it was a shock totally I wouldn't say out of the blue since I know when you have a tremor it can't be good and I waited so long to go to the doctor, but once I was diagnosed it was a shock. It's a lot of uncertainty. Other than knowing what I guess the general populace knows about Parkinson's, there's a couple of famous people with it, then you see what their symptoms are and how they're moving and disabled, and it's quite frightening, and I was not quite sure how fast mine would progress, but after five or six years here I'm still a very active, I would say almost normal person, and it appears to be progressing slowly, which is a very good thing from my point of view.

**Andrew Schorr:**

Well, you know, as I interview enough people who say they're almost a normal person, I think everybody's got something somewhere in themselves or in their family. You mentioned famous people. Of course you and I have talked previously, and many people know of course Mohammed Ali who is diagnosed with Parkinson's over many years and then the actor Michael J. Fox who when he finally revealed it then decided to go off the very popular show he was on "Spin City" I think it was, and you know he shows up from time to time, but he's gone through a lot of treatment, which brings me to Dr. Brodsky about treatment. Some people know that there was a surgical treatment or deep brain stimulations that's used in other surgical neurosurgery that comes into play in Parkinson's, and I know being a cancer patient a lot of us cancer patients say you know hit it early and hit it hard. Well is that necessarily the right route to go? Not to put down Michael J. Fox at all, but how do you determine or what's your philosophy of the way to approach it in a younger person Dr. Brodsky?

**Dr. Brodsky:**

Yes, well deep brain stimulation certainly has given us a great tool and is an excellent option for those appropriate candidates. It's important to realize first of all that the best results we get with deep brain stimulation are really no better than an optimal response to the most potent medicine we have, levodopa, which gets converted into dopamine, which is the neurochemical that becomes deficient in people with Parkinson's in their brains. Deep brain stimulation provides a more constant effect than the intermittent effects that levodopa provides in more

advanced Parkinson's disease. Also, doing deep brain stimulation, while the risk is low, does incur a small but real risk of a serious complication from occurring.

So in light of that we also have to realize that there is still no evidence that deep brain stimulation has a neuroprotective effect. This has been a hypothesis of some and certainly if it did slow or stop progression of Parkinson's disease it would be much clearer that we would want to do this earlier on in Parkinson's disease. I'm certainly a proponent of doing this procedure once one has reached a point where medical management is only offering so much and certainly when people are having what we call motor fluctuations where the medicine works for a short period of time and then wears off. This happens repetitively throughout the day and when people are also getting complications from medications such as involuntary excessive movements that we call dyskinesia, deep brain stimulation has been shown to really improve both of these facets of Parkinson's disease and really can be a wonderful change for people and have a great effect, but it's not for everyone, and in younger patients I think a lot of people would feel that it's a bit aggressive to go right to surgery when there's no evidence that it stops or really significantly slows progression of Parkinson's.

**Andrew Schorr:**

Thanks for that perspective on it.

**Dr. Brodsky:**

Sure.

**Andrew Schorr:**

Now I mentioned, I alluded with Ted, and he's kind of matter-of-fact about it, but it is a big deal, terrifying; I know when I got my leukemia diagnosis at 46 it was terrifying. My wife was terribly freaked out and not surprisingly. We didn't know what to say to our kids, etc. So you say well okay there's a big effect on the family or a potential. How do you manage that?

I want to mention that just two days from tonight when we're doing our live webcast now on September 17, 2008, so on September 19<sup>th</sup> at Doernbecher Children's Hospital at OHSU, there is a symposium for younger people with Parkinson's, and it's called "Healing Tools for Living" and one of the speakers is Kari Lyons who is a social worker with more than a decade of experience helping people and families manage chronic illness, and she'll present "Healing Tools for Living" from the foundation up. There will also be some spouses and young men and women who were diagnosed with Parkinson's in their 30s and 40s. There will be a group discussion and then it wraps up with individual informal discussions and dessert. It sounds good to me.

So if you're in the Portland area or can get down there, just two nights from tonight, September 19, 2008. Here's a phone number to call: 503-494-7231 for September 19<sup>th</sup>, 2008, just two nights from tonight, and there will be this symposium at OHSU.

Dr. Brodsky, now that is an issue for some people, so Ted is working, but sometimes this ability comes into play and to come up with I guess not just medication but sometimes what you call adaptive strategies, right?

**Dr. Brodsky:**

That's right. Before we get to that, let me just also add with regard to DBS, to deep brain stimulation, that of those who have a disabling tremor, and Ted does have a pretty significant tremor, tremor isn't often disabling in Parkinson's early on, but where it is disabling that's often a limitation of medications is that they don't really adequately suppress tremor, and the one motor aspect of Parkinson's that brain stimulation is most effective for is tremor. So for some folks who do have quite a disabling tremor DBS, deep brain stimulation, for that reason may also be a good option, so I just wanted to add that in.

**Andrew Schorr:**

Sure, thank you for that. So it really goes back to what we were talking about earlier is it makes sense to consult with the specialist to understand your Parkinson's situation.

**Dr. Brodsky:**

Right.

**Andrew Schorr:**

Okay. Also back to one other thing you mentioned earlier. Did you say that your track as you and your colleagues have followed it that it may be a little different with people who exhibit tremor than those who do not?

**Dr. Brodsky:**

In terms of?

**Andrew Schorr:**

Progression.

**Dr. Brodsky:**

Yes and actually there have been publications. People have looked at this over the long-term that people with Parkinson's who have the tremor-predominant form, and this has been the common experience for myself and colleagues have spoken to more informally about it, that they seem to progress a bit more slowly than those who have less in the way of tremor and more in the way of rigidity and certainly postural instability as an earlier feature, that those people tend to progress a bit more rapidly.

Now it's not a hard and fast rule, but there certainly seem to be clinical subtypes of Parkinson's. As a specialist we're often asked can you give me, a patient and their family will ask, can you give me a prognosis? Where will I be in five years? Where will I be in 10 years? And it's really difficult to answer that because the rate of progression is variable in different people. So we have a sort of general average that we know about, but because there is this variability from person to person it's really hard to give someone a firm answer.

**Andrew Schorr:**

We've got lots of questions coming in. Several people have sent an e-mail. Our guest tonight is Matthew Brodsky who is assistant professor of neurology at OHSU and also Ted Cahalane who is 50 now but was diagnosed at 43, right Ted? It was age 43?

**Ted:**

Yes, 43 or 44. One of those two.

**Andrew Schorr:**

All right. Let's continue our discussion. I mentioned just about adaptive strategies, so beyond the medications then does somebody sometimes have to use something to help them whether with their walk or with their movement? When does that come into play?

**Dr. Brodsky:**

We are headed with this disease as in other conditions at looking at preventive strategies and doing what we can to slow progression without medication certainly, and I know that today, Fay Horak on this program probably spoke at length about this, but certainly exercise is one component of that. Not only in my opinion do I think that having folks exercise and more specifically walking and not necessarily walking on a treadmill in your gym but getting out and walking on a bit more varied terrain if you can do that I think is going to be helpful for anyone with Parkinson's down the road because eventually people with this do tend to develop problems with postural gait instability, problems with walking, and the more you exercise the muscles in the part of your brain involved with balance the better you're going to be down the road. I feel pretty certain about that.

In addition to that there is now a lot of research from the basic science level with animal research on up that regular exercise, aerobic exercise may have a neuroprotective effect in the brain. So that's a bit more cutting edge research that really needs to be replicated, but it's evidence that's emerging and I'm sure Dr. Horak spoke a bit about that.

## **Questions from Listeners**

### **Andrew Schorr:**

Yes she did, and that replay is on the website. Just go to [ohsuhealth.com/experts](http://ohsuhealth.com/experts), and you can listen to that right after this program or whenever it's convenient for you. We are going to pose some questions to you Dr. Brodsky right after the break. For instance Julie sent one in. She was diagnosed with Parkinson's at just age 24, and we have several other questions from people in this situation wanting your expertise. It's all coming up as we continue our Ask the Experts program brought to you by Patient Power and produced with sponsorship from OHSU. We'll be right back.

Welcome back to our live webcast. Now we're going to really get into the Q&A part of it as you join in. Here's a question, Dr. Brodsky, from Julie. She says, 'My name is Julie and I was diagnosed officially at the age of 24 with Parkinson's disease. I am now 30 and since being diagnosed became pregnant and had a healthy boy who is now two years old. I took Mirapex after my first trimester due to the severity of my tremors. I've been on the same dosage of Mirapex for two years. The intensity of my symptoms decreased after of my pregnancy. Why would a pregnancy affect the severity of my Parkinson's disease symptoms? It seems to be related.' What do you say Dr. Brodsky?

### **Dr. Brodsky:**

Interesting. Well let me start by saying that her situation while maybe not unique is certainly unusual because to be that young and develop symptoms of Parkinson's is quite uncommon. I can't share any anecdotal situations of experience with this because I haven't had anyone with Parkinson's go through a pregnancy, and I'll bet that there is not much out there in the medical literature about this,

So just sort of harboring a guess I do know that there are certainly well obviously hormonal changes that occur during pregnancy, and these can have subsequent effects on how the brain is functioning, and it's an oversimplification when we talk about Parkinson's being a state of just a deficiency in dopamine. In fact there are other neurotransmitters that are affected. These are the chemical transmitters that allow cells to communicate with each other in the brain that are also affected in Parkinson's disease, and probably there is a tie-in there with the state of being pregnant and then postpartum. So I would think that that would have an effect while she was pregnant and then after being pregnant with her symptoms changing. In addition just metabolizing medications can change while you're pregnant and then after pregnancy, so if I heard this correctly she was on therapy during her pregnancy as well as after? Is that right?

### **Andrew Schorr:**

Yes. The third trimester, yes.

**Dr. Brodsky:**

Yes so it's quite possible that she just metabolized the medication differently as well, and that could have had an effect.

**Andrew Schorr:**

Okay here is a question that Ross from up the road from you a ways in Tacoma, Washington, sent it. He said, 'Is there a benefit for early diagnosis? He says, 'Everything I've read sounds like there is so little that is known about the disease I don't know if there is a way to diagnose it early on. What would be the best test to diagnose Parkinson's or any movement disorder particularly early on?' I didn't hear you say MRI or some kind of other highfalutin tests like that.

**Dr. Brodsky:**

No. Actually early diagnosis in this area of research is a particular interest of mine. We do not presently have a way to detect Parkinson's disease before one develops the motor symptoms of Parkinson's like rest tremor, slowness of movement, and muscle rigidity. By the time someone has the symptoms and the signs required to make a clinical diagnosis it's thought that about two-thirds, for example, of the cells that make dopamine in the brain have already lost their function. So a holy grail in this field is to develop a neuroprotective strategy to find a way to prevent cells from dying, to stop the process from progressing. It may turn out to be that to really do this effectively we may need to make a diagnosis of Parkinson's before one develops the typical signs.

That sounds a little paradoxical, but there is research that is evolving in this field. The autonomic nervous system for example is seemingly involved quite early in Parkinson's disease and quite possibly before one develops the more overt signs of Parkinson's, and that may be a window into early detection. Since we don't have a truly potent neuroprotective treatment or combination of treatments it's not critical to make a diagnosis before or what we might consider pre-symptomatic diagnosis. It's not so critical now, although there are a host of interventions that may have a mild neuroprotective effect. We're involved with a couple of studies looking at agents like coenzyme Q10 and creatine. These are actually, we are one site in a nationwide study looking at these two agents as possible neuroprotective therapies.

There is evidence that there might be a mild protective effect of monoamine oxidase inhibitors such as rasagiline. There is evidence both at the bench as well as clinical evidence to suggest there may be a mild protective effect of dopamine agonists. This is debated still in the field, but it may be that cocktail of these symptomatic therapies as well as therapies such as CoQ10 and creatine may together give a more potent protective effect.

So there are a lot of unknowns, certainly nothing that has a potent protective effect that's been proven, but that combined with an early diagnosis may lead to developing a strategy to slow or stop progression, which would of course give us a cure.

**Andrew Schorr:**

I just want to underscore something for our listeners. So the Parkinson's Center of Oregon and the Movement Disorders Program at OHSU is the largest and it's the most recognized movement disorders clinic in the Pacific Northwest, and you can hear a sense of all the research going on. There are approximately 15 to 20 Parkinson's medical and clinical trials going on at all times, and a lot of things have been developed at OHSU, and they've played a key role in this deep brain stimulation we talked about, various neurosurgery treatments, pumps that administer things like baclofen. So there's a lot that's been studied there and why I would recommend if you go there or if you're living at a great distance there may be another Parkinson's center, but it's wise to consult with a specialist, and if you're a younger patient it's not something they see just every day, so you'll want to have a plan and a consultation with someone who's really studied this and continues to study it.

Let's go on to some other questions. Here's one that came in from Vicki in Vancouver, Washington, across the river from you there Dr. Brodsky. Vicki says, 'My husband was diagnosed with Parkinson's disease at the young age,' as she said, 'of 48. He's currently taking Sinemet and Azilect for his treatment. His neurologist never mentioned stages of Parkinson's disease to us or never referred to us as what stage he's in. What are the stages of Parkinson's disease and how significant are they to the patient?'

**Dr. Brodsky:**

Sure, well when we refer to stages of Parkinson's disease, there are different ways to ascertain the degree to which someone has Parkinson's. Probably the most common one is using a unified Parkinson's disease rating score that we use. It's the gold standard that we use in clinical trials. But actually classically the stages of Parkinson's were described in a paper that came out at this point over 30 years ago by Hoehn and Yahr. Melvin Yahr was actually one of my mentors where I trained in New York City who has now passed on, but these stages that they described were developed as a way for us to very quickly communicate with each other as experts to what degree someone had Parkinson's, and they described five, well really six stages, but stage zero being of course absence of signs, but then beyond that whether one had signs on just one side of their body or both sides of their body and then whether those signs involved just the cardinal features of tremor, slowed movement, and rigidity or whether they also had some degree of postural instability, and then as these stages progressed whether it was mild postural instability or more significant impairment of gait and balance and ultimately stage five being someone who is really essentially bedbound.

While the progression through these stages as I mentioned before does vary quite a bit between patients, this is one way of quickly giving a snapshot of to what degree someone has Parkinson's.

**Andrew Schorr:**

Okay, well you know I would always tell people don't get hung up on the stage.

**Dr. Brodsky:**

That's right.

**Andrew Schorr:**

But it's how you're doing.

**Dr. Brodsky:**

Absolutely, and this, you know, that system that I just described is really a very gross oversimplification and in fact it really is just focused on the motor symptoms, and even this Parkinson's disease rating scoring system that we use is also very biased towards the motor features of Parkinson's when in fact it's the non-motor features of Parkinson's later on in the course of the illness that become more of a problem for a lot of people. So some people develop issues related to sleep, and even Ted mentioned this sleep becoming more difficult. Some patients develop autonomic problems; problems let's say with gastrointestinal motility for example. For example, urinary changes and people may develop cognitive problems and memory problems. These are typically symptoms that are later on in the course of Parkinson's, but they become certainly more disabling than many of the motor features for people.

These rating scales have now been recently revised to better recognize some of these non-motor features of Parkinson's. Mood is another issue that comes up, and while depression in some people may be a reaction just to being diagnosed with and living with a neurodegenerative disease, it often predates the motor symptoms in Parkinson's for some people, so these are things that often aren't recognized in a clinic visit unless they're asked about.

**Andrew Schorr:**

Right. Ted, so what's your outlook? You've been dealing with this for seven years or so. You've seen some progression. You're still riding your bike, not as fast, and you're still working every day, and you've got at least maybe three weddings to go to and pay for. So what's your outlook on all this? You know hopefully you're going to live to a ripe old age but with Parkinson's unless they come up with a cure.

**Ted:**

I think earlier that Dr. Brodsky pointed out that people want to know well what will I be like in five years and ten years, and that was certainly some of my questions as well, and we really don't know. Right now my Parkinson's is progressing but certainly at a, I guess mine's at a reasonable pace, but it is quite frightening. How

do I cope with it? I have no choice, so you just accept it and try to make the best of the situation. Fortunately I am not handicapped to any great extent yet, but it's scary to think what the future might bring. There's no doubt about that.

**Andrew Schorr:**

Right, and I'm just going to mention one more time that there is that symposium at OHSU on Friday night I believe it is, anyway September 19, 2008, "Healing Tools for Living" and so if someone is in the Portland area and can get over there, it's at the Vey Auditorium at OHSU's Doernbecher Children's Hospital, and if you want information on that, being a younger Parkinson's patient or a family member, here's the phone number: 503-494-7231. We're going to take another break, and when we come back we will talk more. We've got more questions for Dr. Brodsky. We'll hear more from Ted, and we'll discuss the ten percent or so of the 1.5 million people with Parkinson's who were diagnosed at a younger age and how they can be helped and what the outlook is in research as we get the latest from Dr. Matthew Brodsky from OHSU. You're listening to Ask the Experts brought to you by Patient Power and supported by OHSU. We'll be right back.

**Researching Causes of Parkinson's**

**Andrew Schorr:**

We appreciate you spending time with us tonight on our live webcast as we discuss Parkinson's in younger patients and that means the 30s and 40s although we heard from Julie who was diagnosed at 24. Dr. Brodsky, anybody wonders when they're diagnosed with a serious condition, well what did I do or what environmental factor could I have been exposed to that made this happen? Now Ted's an oil engineer. Somebody else may work with chemicals or maybe they work with pesticides. You know, when I was diagnosed with leukemia my wife looked at the power lines outside and said maybe there were electromagnetic fields. Do we know what could trigger Parkinson's, and I also want you to tell us about any genes someone could carry where that could play a role.

**Dr. Brodsky:**

Sure, well I think the overwhelmingly likelihood is that a parkinsonian syndrome is caused by, for most people, a combination of having some complex genetic predisposition to getting it with certain environmental factors that accumulate throughout life, and that may sound vague, but it's just because I think we really don't know all those potential environmental factors, and we certainly don't know enough about the genetic predisposition.

What we do know based on large epidemiologic studies, so a lot of really good work has come out of the Parkinson's Institute in Sunnyvale for example, is that certain environmental exposures such as pesticides or such as having been exposed to a well water source as opposed to an urban water source throughout your lifetime increases your risk of developing Parkinson's disease, and that's actually been brought down to bench research where certain pesticides have actually been used

to develop animal models of Parkinson's disease. So those folks who have had really heavier exposures to pesticides are at greater risk, but that alone is not sufficient. There are plenty of people who have had heavy pesticide exposure who will go through a long life and perhaps live to be 80 or 90 years old and never develop Parkinson's. So it's alone not sufficient.

The flip side to that are genetic predispositions. So there's just been an explosion in the last ten years in single gene mutations that one can inherit that will predispose someone to developing Parkinson's disease. There's a whole long list of these single, what we call monogenetic forms of Parkinson's disease. If you total all those subtypes of Parkinson's they still account for less than ten percent and probably closer to five percent of all forms of Parkinson's disease. So it's still really a minority, and my suspicion is and I think many others is that genetic susceptibility is more complex than just inheriting a single gene mutation or a single gene trait but probably a complex assortment of a genetic fingerprint, if you will.

So it's really a combination between that and some environmental exposures over time that for most people will lead to Parkinson's. It's important to keep in mind also that people are living, that the greatest risk factor still for developing Parkinson's disease is age. The average age of onset, while we're talking tonight about younger onset, the average age of onset is around 65, and people are just living to be older now because of other medical advances and a general advance in the quality of life in at least some parts of the world, and so that probably is also biasing the prevalence of Parkinson's disease today.

**Andrew Schorr:**

Okay. Here's a question we got in from Sandy in Klamath Falls, Oregon. 'Do most of those with Parkinson's disease have worse symptoms in the morning or evening? I see my primary care doctor next week, and I'm looking for input because I'm not convinced of my Parkinson's disease diagnosis. I wake up in the morning,' as she said, 'almost normal, and on the bad days get stiffer as the day goes on.' So what about that variability within one day?

**Dr. Brodsky:**

Right. While there is some variability some people do report what we call sleep benefit. We don't know the exact reason, but it may just be that your brain is able to accumulate and store and have at it's disposal to release more dopamine when you first wake up in the morning and before you're sort of really worn out by the end of the day. So some people do report what we refer to as this sleep benefit.

Now that's what I've seen in patients telling me about this is that it's not always consistent, and the effect is there but often more mild. If she's really experiencing much more severe swings from the beginning to the end of the day and the diagnosis itself is still in question then maybe something else is going on.

**Andrew Schorr:**

Okay, another argument for consulting with a movement disorder specialist. I just want to mention about OHSU. So Dr. Brodsky, you're at a wonderful center there, and it's designated as a National Parkinson's Foundation Center of Excellence. So if you're in this part of the country, and Ted made the trip from Alaska and it's made a big difference for him, I would recommend that to anyone. I always say when you're diagnosed with something serious and maybe it's a bit unusual like a younger patient, you really need to check in and at least have a consultation with someone who specializes in what you have and then maybe work with you doctor if you live at a distance to help work together on a plan, and I know OHSU does that, and then long-term monitoring and guidance, and as we heard about deep brain stimulation and other approaches, you know when is it right or is it right to pull the trigger on a more powerful medicine or a surgical approach. That's a very individualized decision, and I'd think you'd want a subspecialist to play a role in helping advise you and maybe your doctor if you're getting care at a distance on that.

Ted I want to go back to you before we wrap up. So we talked about your outlook for the future. There are people who may be listening who where this diagnosis is suspected or maybe has been confirmed, and they're really scared. What would you say to them or a loved one who's listening in tonight?

**Ted:**

I guess at that point they would have some type of serous symptoms that show that they indeed are having some type of problem. I think it's important to get of course, like as you guys have been talking about, to get a proper diagnosis, and I really don't see how you can do that other than by going to a specialist for this, and that's why I ended up down in Oregon.

**Andrew Schorr:**

Okay. Then what about coping? So I mean, you're so matter-of-fact buddy, but like there's this seminar coming in to help families. It's okay to ask for help, and I imagine some people, and I know when I was diagnosed with cancer we did. We actually went to a counselor to help my wife and I, you know, kind of get steadied, and that's okay too isn't it?

**Ted:**

I'd say I have not used the other resources that I probably should be just to help cope and help my family adjust. Part of that is because I'm way up here in Alaska, and I, maybe if my symptoms were more severe and I was actually being handicapped in the day-to-day operation that would be a different story. Right now I don't think it significantly influences my family life. I still try to do everything I've done before. If it got more severe then it's probably time to start trying to get outside help just in terms of coping with the disease.

**Andrew Schorr:**

Well I wish you all the best Ted Cahalane in Anchorage. You're in ground zero in this political year, one of the ground zeros.

**Ted:**

Oh yes.

**Andrew Schorr:**

So I'm sure it's exciting around Anchorage. We're not going to talk politics on this program, but you're under the media microscope right now.

**Ted:**

Right.

**Working for Future Advancements in Treatment**

**Andrew Schorr:**

So Dr. Brodsky, we're going to give you the last word. So everybody who's listening says okay Dr. Brodsky, you and your colleagues at OHSU and the ones you talk to around the world, you are devoting your lives to Parkinson's and movement disorders. You have a lot of tools now to deal with the symptoms. You have medications and exercise we talked about and other things you're researching. How hopeful are you that we can make the life or even someone diagnosed earlier in life better as time goes on because the horizon for someone like Ted can be many decades. So what can you give them as far as hope?

**Dr. Brodsky:**

Well I've got to be hopeful, right? This is what I'm dedicating at least part of my career and my time to. At the same time I'm realistic and now seeing really firsthand for a number of years the pace of progress of medical research, especially in something as complex as a neurodegenerative syndrome like Parkinson's disease. I do think that we've made great strides more recently in understanding exactly what causes Parkinson's disease. I think with that greater understanding potentially with evolving research and earlier detection of Parkinson's and trying to come at this through a novel approach and not just replacement in the dopaminergic system, but other strategies that would address the underlying mechanisms of Parkinson's and how to prevent progression of cell death is really they key to the future in research in this area, and I'm hoping certainly within my lifetime, I can't speak for some of my colleagues who have been in the field longer, but I have to remain hopeful that we're going to make strides to be able to slow and possibly even stop progression of Parkinson's disease.

I'll just add also that the kind of research that's going on for a condition like Parkinson's I think has applications for other neurodegenerative diseases, and there certainly are connections between Parkinson's and conditions such as Alzheimer

disease, and we work together a lot of times in this field and learning from each other as the field moves forward. So I am hopeful for the future and where the field's going.

**Andrew Schorr:**

Dr. Matthew Brodsky, assistant professor of neurology at OHSU and at the Parkinson's Center of Oregon, all the best to you. So go team! Everybody listening wants you and the Alzheimer's researchers to make a lot of progress. I just want to mention that people should consider with a long-term condition like this of discussing being in a clinical trial because that's how we patients can team with researchers like you to get the answers that we want for ourselves and for many other people.

**Dr. Brodsky:**

That's right.

**Andrew Schorr:**

Well Dr. Brodsky, thank you. Ted thank you so much. This is what we do on our Ask the Experts program every two weeks, and we're grateful for the support from OHSU and the work they do. They have this nationally recognized center in Parkinson's, and we really recommend people connect with a center like that to help them have a plan, especially if they're a younger patient where that's more unusual in dealing with Parkinson's. We'll be back in two weeks with another edition of Ask the Experts, and again thanks to OHSU for their support.

I'm Andrew Schorr. Remember knowledge can be the best medicine of all. Good night.

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