

## Cancer and Neuropathy

Webcast

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### **Introduction**

#### **Andrew Schorr:**

Hello and welcome to Patient Power. I am Andrew Schorr, and we do these programs every two weeks sponsored by M. D. Anderson Cancer Center. And always we connect with leading experts, some very provocative discussions, the latest in cancer news, and we always meet inspiring patients. I was very lucky in my treatment for leukemia where I had a side effect of the treatment, nausea, and now there are newer and better medicines to manage that, but there are other side effects. We previously talked about fatigue on an earlier program, but there is another big one too in a number of cancers, and that is neuropathy, and that can be the tingling or burning sensation in the hands or feet, nerve damage that could be caused by surgery, some surgeries for cancer, radiation, and unfortunately some of the powerful chemotherapy drugs can cause that as well. We are going to learn more about that and what can be done with the latest thinking at M. D. Anderson to try to manage that to help you not only help you beat the cancer, but go on with your life.

Let's meet another cancer survivor, someone who is doing very well now, but going back two years ago was a scary diagnosis for Janice Swain from Houston in the interior design business. And you had been having bleeding, rectal bleeding if I can say, Janice, and finally go to the emergency room and find out it was stage III colon cancer. That must have been terrifying.

#### **Janice:**

It was. I was knowing for quite some time that it was, you know, I was not feeling well. I was tired and very anemic, and when I was finally diagnosed, it was really a relief, if I could say that about cancer, just knowing what it was and knowing how to deal with it.

#### **Andrew Schorr:**

Well, you got to M. D. Anderson, which was there for you in Houston, and of course I came from Seattle. People come from around the world. And I know you got excellent care as far as surgery, but because it had spread to a lymph node, right, they said we need to do some chemotherapy as well?

#### **Janice:**

That's correct.

## **Diabetic Neuropathy**

### **Andrew Schorr:**

Now, we should mention that for a number of years you have been a type II insulin dependent diabetic, and so that brings up a lot of medical issues for anybody going through surgery or having other treatment as well. And I understand that you had some neuropathy already from the diabetes, not uncommon. What did that feel like?

### **Janice:**

Well, it was not as greatly spread as it became after starting my chemotherapy. It was just in my large toes to the bottom and to the outer edge, and then after the chemotherapy it spread further on to the whole bottom of my foot and then part of the top and also my hands.

### **Andrew Schorr:**

Well, let's talk about that. So first with diabetes but not yet the cancer diagnosis and treatment, you had sort of a lack of feeling in your big toes, and then after the chemotherapy it became, it spread into your hands and feet, and I think you previously told me that when you would get in bed at night just pulling up the covers hurt?

### **Janice:**

Oh, absolutely. I would have to uncover my feet and sometimes just hang them off the bed.

### **Andrew Schorr:**

Okay. And what about with your feet or just wearing shoes during the day or taking them off at night?

### **Janice:**

Wearing shoes, I don't know if it was just the tightness or having the pressure on them because I stand a lot, it was okay. I could deal with that, and just, you know, having your mind off of it because you are busy doing other things would kind of eliminate so much of the pain too, but as soon as I would take my shoes off is when I would start feeling the neuropathy more.

### **Andrew Schorr:**

Now, we should mention that neuropathy can affect people in different ways. Now, I think good news for you, Janice, was right as you were coming out of the surgery and recovering from that you met one the M. D. Anderson doctors who is devoted to helping. And that's Dr. Jeong Oh. He is assistant professor of medicine at M. D. Anderson in the general internal medicine department, but he is also in charge of helping people manage the effects of cancer treatment, and there is a whole center

there in general internal medicine for that. So he walks in, and then he became a trusted relationship as you managed and managed better with the neuropathy. Do I have that right?

**Janice:**

That's right.

**Causes of Neuropathy**

**Andrew Schorr:**

Well, let's meet Dr. Oh who is with us today too. Dr. Oh, this problem of neuropathy is really not an insignificant one in cancer care, is it? I mean, we have these powerful modalities of treatment, but often there is this side effect, and right now we are working hard to have better ways of managing it.

**Dr. Oh:**

Yes. First of all thanks for having me. Unfortunately this is a very common side effect. As you mentioned it can be from the cancer by itself, radiation, surgery, and most commonly from chemotherapy.

**Andrew Schorr:**

Now, one of the things that I noticed from just reading up on this, so people can have it in their hands and feet, but the nerves go to the muscles, so it can affect movement, and even, it looked like, even bowel and bladder issues as well.

**Dr. Oh:**

Yes, absolutely. Even though [the effect] on the bowel and bladder movement tend to be more [commonly] due to local treatment either directed by surgery, radiation, or the cancer by itself, chemotherapy tends to affect the bowel movement by other mechanisms more than through neuropathy.

**Andrew Schorr:**

But typically it is what Janice was experiencing where you might have pain or numbness or tingling in your feet or your legs or your hands. That's the most typical?

**Dr. Oh:**

Yes. I think because we tend to give chemotherapy more commonly than any other treatment, at least [more than other] treatments that give neuropathy, that's what you tend to see most commonly the feeling of pain, or numbness [sensory neuropathy]. And then rarely you can have a little bit of motor neuropathy that most patients don't even realize they have because they just feel little weak and they think this is just part of the treatment they are receiving.

**Andrew Schorr:**

And of course the concern would be if you were having movement problems, let's say you can move but you don't always have the awareness of how you are moving, let's say in an older patient you could worry about falling, right?

**Dr. Oh:**

Oh, absolutely, because proximal muscles are being more affected, standing up from the bed or the chair can be a big issue for them.

**Andrew Schorr:**

All right. Let's understand. What is it about certain drugs that causes this in the first place? So for my leukemia that was not an issue, but I know in some other course regimens and for instance what Janice had for her colon cancer it's not uncommon. I have interviewed people who have been treated for multiple myeloma, and neuropathy is a concern there. So there are certain cancers where certain drugs cause this effect. What is it about the drugs? What's happening to the nerves?

**Dr. Oh:**

I am very glad to hear that you were very lucky not to have it as leukemia is also one of the cancers that I need to treat for neuropathy. So there are major ways different kind of drugs that can affect the nerves. One is basically by damaging the nerves directly, because with chemotherapy we are trying to make it difficult for the cells to multiply, and the little organs that the cells use to multiply is the same ones that the nerve cells need to use to transmit the information from one cell to another. So by affecting one, you are affecting the other one at the same time.

The second mechanism is that there are some products that we produce that help heal the damage that chemotherapy does, and some chemotherapy seems to make us lose the ability to either produce or to retain that product in the body.

**Andrew Schorr:**

I know that there is a lot of research going on in the labs at M. D. Anderson trying to understand what is it about these drugs that cause the neuropathy, and also I understand that it's variable in patients, right? Not everybody--like I had nausea big time with chemotherapy and the monoclonal antibody I had. I don't know what was the bad guy there. But at any rate that was a big thing for me, and it got worse as we went on, but for other people it varies, right?

**Dr. Oh:**

Uh-huh. And really depends on what kind of [medical] problems you had before [chemotherapy] and also a little bit on your genes, even though that part we haven't understood the latter very well yet. So patients like Ms. Swain who has diabetes, they already had previous damage to the nerves. So patients who have previous damage [to the nerves] have much higher risk of developing neuropathy

or at least to develop neuropathy that is more severe, and they [can] notice it [more easily]. I think there are many more patients who develop neuropathy that they don't even notice they have [it].

The other issue is the way we metabolize some nutrients that we have in our body differently from person to person. And in some cancers, like testicular cancer, we found out that [for] some products like glutamine, which is an amino acid, some patients don't metabolize it very well, and these patients have a much higher risk of developing ototoxicity [hearing loss] and nerve damage also.

**Andrew Schorr:**

Now, let's back up for a minute. So is there a way to test for that ahead of time, or is there anything being done like that, or is that in the lab to say can we predict which patients will have neuropathy, and then we adjust the treatment plan based on that? Or are we not there yet?

**Dr. Oh:**

Unfortunately we are not there yet. For example, let's look at glutamine. There were studies trying to predict that [deficiency in the metabolism of glutamin], but we found out that predicting it would not help because giving glutamine has not been proved to be completely safe [in patients with testicular cancer] . So that was a path we could not follow. We need more studies to come out on that. And most of the tests they have done so far has been after the treatment, after the first [cycle of chemotherapy] they will try to predict who is going to have more neuropathy not really before starting the treatment.

**Andrew Schorr:**

All right. Now, the problem of course if neuropathy gets really bad and can't be managed is then you have to reduce the dose of the cancer-fighting medicines, and I know in Janice's case there was some dose reduction, although happily Janice now two years or so later, she appears to be cancer-free. And, Janice, I hope that goes forever as you have your checkups. But that's the whole question, if the dose was arrived at for a certain reason, and you are trying to stay I think as you say on dose and on schedule. So tell us about adjusting the dose, and this sort of balance between fighting the neuropathy, limiting it, and yet fighting the cancer.

**Dr. Oh:**

Well, thankfully [for] most of [chemotherapy] drugs, neuropathy is not a dose limiting side effect. Unfortunately for what she received, oxaliplatin, neuropathy is a [dose] limiting factor for her. For most of the other drugs there are other side effects that are more frequent than neuropathy, so they become the dose limiting [factors]. And sometimes, unfortunately, the neuropathy appears quite late, sometimes even starting to become severe after the chemotherapy, so dose doesn't get adjusted for that.

Of concern is that the new drugs are coming out because where they [the drug companies] have concentrated so much on improving other side effects that now they are able to increase the dose [given to the patient], and now the neuropathy is going to become an issue on limiting their dose [like Abraxane].

### **Communicating with Your Doctor**

#### **Andrew Schorr:**

Well, so I think there are some important issues to talk about as we continue. The first is communication because you don't really have, I would think you don't--it's not like you can do a CT scan or something and see neuropathy. It's communication between the patient and the healthcare team, so I want to talk about that. And then also of course we are going to talk about how can you at M. D. Anderson help people as you have helped Janice in limiting the effects of neuropathy so people can go on with their lives.

Let's just take just one minute before we take a brief break, Dr. Oh. Let's talk about communication. How important is it for the patient to say, you know, I don't know if this is connected by I have got this funny feeling or this tingling or--and as you say sometimes with movement things you are not even aware of it, but communication and even just with a checkup, the analysis you all do to try to look for signs of neuropathy as well?

#### **Dr. Oh:**

Yes. I think that's the most important message I would have for the patients is to tell them that it's okay to tell about all their problems to their doctor. Sometimes they are so focused on fighting the cancer that they feel like "oh, this is not important enough for me to mention to my doctor" and it's very important they mention everything that they feel so we can adjust [the treatment]. And sometimes, like in case of Janice because she had diabetes, there were some products that we could try to give to try to minimize the neuropathy from coming instead of waiting until we have the full effect of it.

#### **Andrew Schorr:**

Right. Well, we are going to talk about that, but of course there you were already on the lookout for it because Janice already had some neuropathy from diabetes. Other people maybe don't have any history like that, but yet these subtle signs, sometimes not so subtle, can creep in.

Janice, we are going to take a break in a second, but before we do what would you say to people listening about the importance of very active communication on what they are feeling so that they can get some help?

**Janice:**

Well, first of all M. D. Anderson is great with giving you literature and a total book actually on symptoms and things that could happen. And, you know, you just do a rundown. And as you are going into it or before you start your chemo, it's good to read it and then communication and finding a doctor like Dr. Oh that you can communicate with, and he listens well, and he responds well. Those things are just most important.

**Andrew Schorr:**

Right. I echo that. I believe that is so important.

Well, we are going to take a brief break, and when we come back we are going to talk with Dr. Oh and Janice from the patient perspective on what can be done now to manage neuropathy. If you are experiencing it, how it can be limited, how you can go on with your life and be a cancer survivor who can enjoy life hopefully to the fullest. Much more coming up as we continue our discussion on neuropathy on Patient Power brought to you by M. D. Anderson Cancer Center. We'll be right back.

**Signs & Symptoms**

**Andrew Schorr:**

Welcome back to Patient Power as we continue our discussion about neuropathy, that tingling, burning sensation typically in the hands and feet, could be pain as well. And we were talking just before the break about the importance of communication between the patient and their doctor, and so that this is noted. And sometimes it can be subtle, and sometimes not so subtle. Let's go back to Dr. Oh who specializes in studying the effects of cancer treatment and particularly neuropathy.

Dr. Oh, what should people be looking for?

**Dr. Oh:**

Well, obviously there are things that are obvious to the patient also, like the numbness and the feeling of pain usually in the tip of their fingers and feet, and those are the things that the patients tend to mention, but there are other things that do come before that. And the first symptoms in fact are a change in the speed you can write, your handwriting may get worse, and you may notice that your ability to manipulate small objects like buttons and picking up small objects may become very difficult. So these [symptoms] may come even before the numbness and the pain.

The other symptoms they may notice is that they have trouble touching cold objects. They may get pain by doing that. And also they may notice some weakness in their ability to stand up, their ability to comb their hair, and these may be a first sign that the muscles are being affected also.

**Andrew Schorr:**

Janice Swain, what about for you? So there you are in your interior design business, and you are trying to be working after your surgery and maybe during and after chemotherapy. Did you notice any of these manipulative issues in your hands?

**Janice:**

Oh, absolutely. And Dr. Oh mentioned just the coldness too. The first time I had that feeling I think it was like my second--during my chemo the second time. And I washed my hands, and it was just, you know, tap water, and it was just extremely painful. I felt like I had just put my hand in fire and pulled it back. And I had read about it, but I hadn't, you know, I hadn't had the problem yet. So it was like oh, my goodness, what's going on? So I immediately turned some warm water on, and this was at M. D. Anderson. That was an issue. And then just doing my daily, you know, like looking at fabrics, flipping with my hands was painful. Writing, Dr. Oh had asked me, and I said oh, my goodness, I have the hardest time trying to write so that I can even legibly understand what I have written. Doing, you know, buttoning anything, putting on jewelry, just the basic stuff was difficult.

**Andrew Schorr:**

Now, let's carry this further. That's during the day. What about at night? So we talked about it being painful to pull up the covers. How did you sleep?

**Janice:**

Well, I started with some medications that helped a lot, but then I had been, you know, just keeping my feet off the bed so that they didn't touch anything, which doesn't exactly make you comfortable lying in bed and trying to go to sleep. Dr. Oh suggested actually wearing some snug socks, and actually putting on gloves, and that did help a lot, just kind of I guess caressing them and making them, the tissue I guess, a little more tight and firm. I don't know exactly how it worked with the nerve endings, but it really did seem to help.

**Treatment Modalities**

**Andrew Schorr:**

All right. Well, let's ask the expert. Dr. Oh, so help us understand that. With these sorts of problems how can you help? And what are these, you know, she mentioned some of these modalities. Tell us maybe some of the things you recommended in Janice's case and also how there may be other approaches for other people.

**Dr. Oh:**

So there are several different approaches. One would be medications. Another approach would be supplementation with nutrients. And the third one is behavioral changes that can help with the symptoms. So she was mentioning about the behavioral changes. With chemotherapy, particularly the type that she has received, there are two issues. One, being sensitive to cold objects, and as she said tap water was cold for her. And by trying to avoid the nerves from becoming cold helps, so the socks and the gloves can help. And also the fact that by stimulating the pressure nerves, and with this chemo the pressure nerves are not really affected, we will keep her brain distracted from the pain information that's coming from touching cold objects. So that's one thing that can be done for the patient is to try to keep [hands and feet] warm during the night, and during the day also if the day is cold.

The other one is try to prevent the neuropathy from coming if we know that the patient is at a higher risk. And that we can do with--two food supplements are available that in theory can help. One a glutamine, which I personally am a little bit reluctant to use. We feel that we need a little bit more research to prove the safety because glutamine, in theory, could make the cancer cells to grow faster even though clinical studies didn't show that.

But the other one is [L-acetyl] carnitine, which is a product that our body produces but the chemotherapy makes you lose it in the urine. And the carnitine is needed to increase a product [nerve growth factor] in our body that helps heal the nerves, so it can be given with the chemotherapy to try to prevent the neuropathy. Once you already have the symptoms, then it depends on the symptoms what kind of medication we will give.

**Andrew Schorr:**

Now, what about exercise? I'm not clear whether exercise is a good thing or not.

**Dr. Oh:**

I have not seen any good studies showing a proven benefit from exercise to treat neuropathy yet. [It does help you cope better with the effects of neuropathy]

**Andrew Schorr:**

There are health benefits, of course.

**Dr. Oh:**

Sure.

**Andrew Schorr:**

But the question is will the exercise reduce the neuropathy.

Now, what about this whole area, and you touched on it there, of complementary and alternative medicine, and I know of course there is a center for that at M. D. Anderson as well. So there is still research going on, vitamins, you know, all sorts of things we wonder can they make a difference.

**Dr. Oh:**

Yeah. There are a lot of products in natural and complementary medicines that seems to show some, how can I say it, some hope. Not many of them were studied very well. If you have severe pain, sometimes I recommend patients to get acupuncture that may have less side effects than some of our pain medications.

For natural products there are some products that have been looked into that I reserve for the later use [after I have exhausted other options] like vitamin E, which seems to show some benefits, however there is some other studies that show that high-dose vitamin E can have other complications for your body, so I try to stay away from them. Vitamin B, there is some controversial literature on that. And I think the one that has been studied the most in many different diseases and shows very minimal side effects and benefits in all different areas has been the L-acetyl-carnitine which also helps prevent hepatotoxicity from the chemotherapy, helps with your fatigue level, and can help with the memory and the neuropathy that you feel.

**Andrew Schorr:**

I was reading an article that quoted Dr. Dougherty, who is in research there in the lab, related to these effects of neuropathy and pain, etc., and he was mentioning there that he said to decrease symptoms patients are asked to eliminate smoking and alcohol and exposure to insecticides. Tell us about that. What's the tie there?

**Dr. Oh:**

To be honest I don't know the exact, direct tie between the smoking and alcohol [and neuropathy]. Obviously we know that the alcohol by itself can cause neuropathy if you drink for a long period of time. And also usually your diet tends to change if you drink a lot of alcohol, so there are mechanisms also in the liver, because you shift how your liver works, and both glutamine and carnitine are produced in the liver. So there may be some effect there, but I am not very aware of direct effect. And insecticide by itself can also cause damage to your nerves so you don't want to add [further damage] into that.

**Andrew Schorr:**

And smoking of course is not good for your circulation or nerves either.

**Dr. Oh:**

Your circulation and the amount of oxygen that will be reaching your nerves is reduced [when you are already have lower levels of the enzymes that help produce energy at all different levels].

**Andrew Schorr:**

What about what you eat? So we hear a lot about antioxidant vegetables. Any knowledge there that that can make a difference, that we should eat a certain diet if we are experiencing neuropathy?

**Dr. Oh:**

Well, I haven't found any specific diet that is really helpful. So far the research has been more in using specific products that are nutritional supplements, but usually the diet does not provide enough quantity to overcome the deficit.

**Andrew Schorr:**

Dr. Oh, one of the things we wonder about is is this a one-way trip. So if somebody has nerve damage from the cancer fighting drugs, can--after the therapy, can these nerves, and I know nerves don't change rapidly, can they recover, or are we stuck with what we get?

**Dr. Oh:**

Well, it depends really from the, for example, from the drug that you take. In the case of Miss Swain, for example she took oxaliplatin. Most of the patients who receive oxaliplatin, their neuropathy is very short-lived. It gets better within weeks from the chemotherapy. But in her case with the diabetes and the fact that she felt the more severe symptoms a little bit later in the chemo, that was a way that we knew she was going to have the type of damage that either lasts for several years or may last forever.

Overall most patients who get neuropathy, even without treatment, they improve somewhat in their symptoms. The body recovers somewhat. But usually there is not 100 percent recovery. If you did not recover by six months, that usually means you are going to stay with that neuropathy for a long time.

**Andrew Schorr:**

What I have always been told, though, is that's where communication is so important. So if people are experiencing the very early signs of neuropathy, you and the healthcare team want to hear about it right away.

**Dr. Oh:**

Absolutely.

**Andrew Schorr:**

Okay. Janice, let's get some practical advice for you. So first of all, what's been working for you, and have you seen an improvement over time?

**Janice:**

I have seen an improvement. My hands are better. I still feel a little numbness to the tips, but not nearly as bad as it was during the chemotherapy and right after. My feet, I still--they still hurt at night, and basically when I take my shoes off I feel like there is a piece of cardboard that is just totally attached to the bottom of my feet. That's the best way to explain it. And then I have, I still have pain in my feet. I tried to reduce the Neurontin medication that I'm on and noticed that it was just unbearable at night really to be able to sleep or have any kind of relaxing night whatsoever.

**Andrew Schorr:**

So medicine then, having the right dosage has helped?

**Janice:**

Absolutely.

**Andrew Schorr:**

So Janice, you know, we have all gone through--you and I and so many people listening have gone through state-of-the-art cancer care, and we are going on with our lives and doing pretty well. That's really what it's about, isn't it? It's fighting the cancer. We wish we had perfect treatment modalities where there was no price to pay, no side effects to beat the cancer, but when you look back on this, how would you say it? I mean, nobody wants neuropathy, and you certainly didn't want it with your diabetes or even to have diabetes, but how is it compared to the alternative?

**Janice:**

Oh, I would go through it again and risk any symptoms to go through the possibilities of the chemotherapy helping. That's a risk we have to take, and we can, you know, I think all of us can deal with the side effects if we have a good doctor that's cheering us on and saying we are going to get better, or we are just going to deal with this and get through life and just take a positive attitude.

**Andrew Schorr:**

And Dr. Oh is that partner for you?

**Janice:**

Absolutely, he is. He has been a great doctor.

**Andrew Schorr:**

Dr. Oh, now standing beside you there not only are great folks in the clinic but also as I mentioned a lot of research going on at M. D. Anderson. Nobody is satisfied with where we are now with neuropathy. Certainly there has been help, and you

are on the forefront of that, but when you have conversations with folks in the lab and knowing the progress that has come out of M. D. Anderson in so many areas, are you confident that we will be able to do better?

**Dr. Oh:**

I am confident we will be able to do better. It's going to take time, and I think the biggest challenge in this one area is that we are doing progress in the lab and the research, but we have not been doing a lot of progress in communicating these advances to the primary care doctors in the community. Many times patients have to follow with them [primary care physicians in the community], so that's where lately I have been putting my focus on. I need to know where the other doctors stand in their knowledge and how can I help them to be able to provide better care. We have close to 13 million survivors now, and the comprehensive cancer centers cannot not handle all of them. We need to help the community doctors to be able to help the survivors.

**Andrew Schorr:**

Right. Well, I am all about that too, and so I am delighted that we can be doing this program on the Internet. So wherever you may be, whether you are an M. D. Anderson patient or not, this is an important discussion with your doctor or your healthcare team, wherever they may be, alerting them that you are experiencing what we have described as some neuropathy and asking questions. Are there things we can do? Hey, I heard about this, I heard about that. Ask questions. And if you are not getting good answers, then seek another opinion as well, whether it's at M. D. Anderson or another major cancer center. And for the folks who go to M. D. Anderson, they are blessed if they get to have a partner like you, Dr. Jeong Oh. Thank you so much for being with us, Dr. Oh.

**Dr. Oh:**

Thank you very much. I really appreciate the opportunity to be able to bring more information to the patients and survivors.

**Andrew Schorr:**

Well, thank you. All the best.

And, Janice, all the best to you. Now, is there anything you want to say to Dr. Oh while we have got you in a public forum here?

**Janice:**

Oh, just many thanks. He came in at a time that I needed him, and for other, you know, for other reasons, for my diabetes, and then the other side effects occurred, and he was able to help me through all of that, and I certainly appreciate it.



**Andrew Schorr:**

Well, all the best. And I am delighted with the people I have on Patient Power and to see this partnership between patients who are very involved in their care and practitioners who really want to help and bring state-of-the-art approaches to help them get better. So it's really thrilling for me.

I want to mention what our next program is about. We will be doing a broadcast on September 16th on advances in the treatment of testicular cancer, and our expert will be Dr. Lance Pagliaro, and he will talk to us about testicular cancer. Of course there are famous people like Lance Armstrong who have been treated successfully for it. We are going to hear the latest in that next program.

This is what we do on Patient Power with M. D. Anderson every two weeks connecting with leading experts and inspiring patients like Janice Swain today. We like to say that knowledge can be the best medicine of all. I am Andrew Schorr. You have been listening to Patient Power brought to you by M. D. Anderson Cancer Center. Thanks for joining us.

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