



Pain and Parkinson's with Dr. Miyasaki
Monday, April 6, 2020

Melani Dizon ([00:00](#)):

Hello and welcome everyone. I'm Melani Dizon, I'm the director of education at the Davis Phinney foundation and today I am happy to have Dr. Janis Miyasaki with us to talk about pain and Parkinson's. Hi Dr Miyasaki. Thank you so much for joining us.

Now about Dr Miyasaki. She is the Director of the Parkinson and Movement Disorder program at the University of Alberta. Her area of interest is in novel patient care delivery, including development of the first neurologist led palliative care program in the world, positive psychology and Parkinson's and communication skills. She's been a speaker for us at The Victory Summit event most recently in Seattle at the end of 2018. And her talks always get rave reviews. So we're really excited to have her here today.

So I'd love to get started by talking broadly about pain. According to some estimates, somewhere around 60 to 80% of people living with Parkinson's report pain. Is that percentage accurate to what you see in your office? And is this pain a common concern that you hear from your patients?

Dr. Janis Miyasaki ([03:24](#)):

Well, pain first of all is a very personal experience. So what one person calls pain, another person might just call an ache or a twinge or it feels like a pulled muscle and they don't really pay much attention to it, nor does it inhibit their abilities. So that estimate seems a little high for most people who have dealt with Parkinson's for a long time and it probably reflects the most generous, broadest view of what pain is. And so I think we have to keep in mind that some people are very stoic, will never complain about pain. Other people if they get a cut on their finger, it's like a life and death situation and you know, they, they come with the big bandage around their finger. So it, I, I would take that with a grain of salt.

Melani Dizon ([04:31](#)):

Okay. So what are the different types of pain experienced by people with Parkinson's?

Dr. Janis Miyasaki ([04:36](#)):

Okay, so people with Parkinson's can experience similar types of pain to the general population. Probably the most common once you get over 40 is musculoskeletal pain. So those aches and pains from misadventures in your youth when you went skydiving and maybe you shouldn't have when you tried to run the Boston marathon and you shouldn't have. So those things tend to become reactivated as we get older and emphasized. And additionally Parkinson's can exacerbate those musculoskeletal problems or make those musculoskeletal problems worse. Because when you have Parkinson's, the tendency is not to move as much. And then for many people who have arthritis, movement actually helps even rheumatoid arthritis.

The next type of pain is something called neuropathic pain. And that's a fancy way of saying we believe the pain is starting in your brain, not that it's in your head, but really that because of the wiring in your brain, it's perceiving things that shouldn't be painful as uncomfortable or is creepy and crawly or tingly. And this is also seen in Parkinson's disease.

And then we think of pain that is related to treatment. So people often say as the pills wear off or when they start to work. I know because my hand starts to take this posture and cramps, it lasts for 10 minutes to 30 minutes. And then I know I'm going to be off.

Melani Dizon ([06:26](#)):

Okay. So the musculoskeletal pain you know, a lot of times people, you know, we are, we highly emphasize exercise and so people will come to us and say, but it hurts. And so what has been your experience in terms of the time that it takes for, let's say somebody is experiencing that type of pain that they do start to exercise and move more? How do they know? You know, there's those, those people

sometimes that haven't exercised a lot, right? And then we tell them, Oh, all of a sudden now you better do this every single day. So what is, what is that sort of pain pathway? How long does it take for those to kind of kick in to start feeling better?

Dr. Janis Miyasaki (07:08):

Hmm. That is a good question because you're right, we do tell people to exercise and many people have been sedentary for years, if not decades. And the commonest trait among people with Parkinson's is that they're very diligent. If you tell them to do something, many of them are going to, okay, I've got an exercise, I'm going to exercise two hours every day. And as one of my patients said for me, yoga becomes a competitive space. And I think the first thing to know is just like any athlete starting out, you never start trying to run the marathon. You start gradually, you start walking and then you increase the pace. And a good rule of thumb that I use for my patients is that they should do a moderate degree of exercise 35 minutes, five times a week. And a moderate degree of exercise is being slightly short of breath while trying to keep up a conversation and do the exercise. So it doesn't mean you should be gasping for air. It means that you're slightly short of breath and as your endurance, both your cardiac and your lung endurance improves and capacity improves and your joints most importantly accommodate to this increased exercise, you will find that it takes more and more effort to get to that slightly short of breath.

And that's a nice natural way to tell how intense your exercise should be. Where some patients, I'm telling them to take their medications before they exercise can be helpful. So if they take their medications at eight to try an exercise at nine or 10 when the medications are going to be working, or for people who have a lot of musculoskeletal pain to take some Tylenol or acetaminophen or ibuprofen prior about an hour prior to their exercise to reduce some of the discomfort.

And then for most athletes, if you feel too much pain, that's a sign that you've, you're actually doing something wrong. Either the form is wrong or you're doing it too intensely. And so I would not want people to discount pain as a sign that maybe something's not right. And finally we have to recognize that because people have been sedentary for a long time and we are now seeing an increased link between diabetes and Parkinson's disease, that perhaps the pain is due to something

else. Maybe it's not related to Parkinson's or osteoarthritis. Maybe it's related to having a herniated disc or maybe it's related to another medical issue. And so people should keep that in mind and have a good connection with their family doctor, not so that the family doctor is always saying, Oh, it's your Parkinson's. But keeping an open mind because people would, Parkinson's can get other illnesses. I always have to remind my patients of that. You're just as likely as everyone else to get something else.

Melani Dizon ([10:43](#)):

Right. Which is why it's also important to, you know, yeah, keep a good relationship with just your family doctor who's going to be on track and keeping track of all the different things that are coming up for you and refer you to somebody else. Do people who experience pain the most tend to have motor symptoms as their dominant feature or non-motor symptoms? Or do they experience pain equally?

Dr. Janis Miyasaki ([11:38](#)):

So non motor symptoms pain would be a non motor symptoms. Right. And in general non motor symptoms increase with the duration of the illness. So we often in our clinic we do the non motor symptoms questionnaire at every visit and we see that at the beginning of the illness, at least when they first come to us, almost everything is a no. And then as the illness progresses, we see more and more yesses. And in fact, after five years, if we don't see a lot of yesses, we either wonder if that patient will never complain of anything or if the diagnosis is correct.

Melani Dizon ([12:24](#)):

Interesting. you also talked about the relationship with Parkinson's and diabetes. Can you speak a little bit more about that?

Dr. Janis Miyasaki ([12:34](#)):

Yeah, so we are noticing an increased association between diabetes and Parkinson's. And as many people may be aware more recent research in diabetes seems to indicate that a lot has to do with inflammation in your body because when you have fat, it's not everyone thinks of fat as something that just sits there. But in fact, fat is an organ that is living and when we get too much visceral fat that is

increasing inflammation and there has been long, a long standing theory that Parkinson's is related to inflammation. And this is why the investigators at Washington university had attempted to study you using medications to reduce inflammation to see if that would reduce the symptoms or stop the progression of Parkinson's. And unfortunately that study of nilotinib was negative. Okay. Interesting. Okay.

Melani Dizon ([13:45](#)):

So that's something that everyone's going to keep an eye out for. How does brain, this is a question from a viewer. How does brain originated pain differ from overdoing exercise? And how can you tell the difference?

Dr. Janis Miyasaki ([14:00](#)):

So neuropathic pain in general tends to be fairly consistent throughout the day, whereas overdoing exercise, it's after you've done too much exercise. So I restarted running recently and I got plantar fasciitis ironically two weeks after my colleague got it. And I said, Whoa, that's unfortunate for you. And then two weeks later I got it. So karma is, is kind of painful. So when you know that you've increased your activity and then you start to feel knee pain, you think, Oh, that's probably because I increased my activity and I can't tell you how helpful a physiotherapist can be in dealing with that. You know, we often look to the movement disorder neurologist. When I first started the movement disorder neurologist was everything to the patient. But I think we realize now that so many team members have an important role to play a physiotherapist. When I had a tear in my anterior cruciate ligament, he diagnosed it. My family doctor said my knee was fine. My physiotherapist immediately after just doing it, the view maneuver said, you have a tear of your ACL and here's what we're going to do. So if you have pain that's associated with your activity or worst after your activity, I would encourage people if you can afford it or if you have access to it to access a physiotherapist because their ability to examine the musculoskeletal system is just superb.

And then if you have neuropathic pain, it does tend to be more consistent. And as opposed to that aching you get when you are doing an activity, the neuropathic pain is just this creepy crawly uncomfortable sensation and it is spontaneous. It's regardless of what activity you were doing, it tends to be present. Although when

people are quiet and resting, it tends to be more noticeable probably because they're less distracted.

Melani Dizon ([16:16](#)):

Hmm. That makes sense. Somebody asks a question about Tylenol. They had heard that people with Parkinsons should not take Tylenol. They should only take Aleve.

Dr. Janis Miyasaki ([16:27](#)):

Well I have never heard that recommendation. Aleve is a nonsteroidal antiinflammatory and so we have to be careful about taking it because it can be hard on the stomach and it can cause peptic ulcer disease and actual bleeding from the stomach. So taking a leave can be fine in small amounts, but acetaminophen is actually a mainstay and the first step of the pain ladder that we try both physical methods like applying cold, applying heat. But I would just caution with heat if SA, if a person is immobile letting them lie or sit on a heating pad unattended is not good because they may not be able to move off the heating pad. But if someone is able to control it themselves, using a heating pad can be helpful. And then using acetaminophen or ibuprofen is recommended as the first step on the ladder. There is nothing specific about Parkinson's that would make acetaminophen contraindicated.

Melani Dizon ([17:44](#)):

All right. So it would be something that you might have your own, like your own issue with it, but in general it's not a problem. Where does dystonia fit into this, this pain, these three different types of pain and, and what are some of the ways that people can manage that?

Dr. Janis Miyasaki ([18:01](#)):

So dystonic pain is that pain that I first described. So for the person who asked, it tends to be either the hand or the foot and it's in a cramped position, typically first thing in the morning or when the medications wear off. So the general management is to increase the dose of medication and to help it last longer. However, some people who have escalated their dose a lot because they are intolerant of the off periods, usually because of anxiety those patients can get very bad dystonia and in

those patients decreasing the dose can be very helpful. Okay. So that's the other, Oh, sorry. No, go ahead. If just you guessed to be either prolonged, severe and disabling and someone still responds very well to Levodopa considering functional surgery. So deep brain stimulation or a lesion or considering can be helpful.

Melani Dizon ([19:20](#)):

Great, thank you. What about, is pain often a side effect from medications or, or is that not tend to be an issue or is it not something that you can really pull apart and say, Oh, this is a side effect?

Dr. Janis Miyasaki ([19:38](#)):

Generally, if the pain is on the sides that is most effected by the Parkinson's and it tends to occur in the same schedule as the medications, then you can say that it's related to the Parkinson's and its treatment. The challenge is that of course if we stopped the Levodopa, you would not have any painful dystonia, but you would also not be on ever. So it is one of these issues that it is the progression of the illness, the inability of the brain to handle the Levodopa as it did when you first started taking the medication so that it was smooth all the way through. As time goes by, the brain becomes less able to handle Levodopa smoothly and then you get these Hills and valleys of responses as well as the painful dystonia. And for some people disabling dyskinesia is, which can also be very painful, particularly if they're violent or involve the neck. People can get a lot of pain.

Melani Dizon ([20:49](#)):

Okay. somebody was saying that they experienced very tightening of muscles, you know, cramping at night. Is that, is that a specific thing to, to Parkinson's? As that, you know, I think people a lot of times experience restless leg and those kinds of things and she said that he said that he often applies lidocaine patches to it. It usually resolves after 30 to 40 minutes. But is this something that is so common that it probably is related to Parkinson's or is this something maybe on totally unrelated and something that they should maybe see a sleep dump or something?

Dr. Janis Miyasaki ([21:26](#)):

Yeah, the only way to tell is for the patient to speak to their neurologist or their family doctor, whoever is writing the prescription for the Levodopa and to see if a dose taken in the middle of the night can help relieve that symptom. So many of my patients do complain either of tremor emerging in the middle of the night that is very bothersome or that kind of cramping and pain in the middle of the night or stiffness that is very difficult and uncomfortable. And I often tell people to take another dose of Levodopa and put it at their bedside, take it when they wake up to go the washroom and see if that will help last through the night. Because when you think about it, most people sleep for a very long period of time and that's the longest period of time that our patients go without any medication.

Melani Dizon ([22:25](#)):

Great. somebody asked if there's any link between Parkinson's and pinched nerves.

Dr. Janis Miyasaki ([22:34](#)):

No. There is no link between Parkinson's and what is commonly known as pinched nerve is a herniated disc that then actually it causes pain because it herniates in a way the disc between your vertebrae comes out and it actually presses on the nerves as they exit the spinal cord or the spinal column. And really the only association would be Parkinson's tends to be higher risk when you're older and people tend to get herniated discs in their lower back as they get older as well.

Melani Dizon ([23:19](#)):

Okay, great. So how do you see pain impacting the mental health or mental wellbeing of your patients?

Dr. Janis Miyasaki ([23:29](#)):

Well there are two answers to that question. One is the people who are already anxious and depressed tend to rate their pain much more highly than someone who is not and depressed. So this is one factor. And then the other is that pain that is armory lurching is of course a cause of depression and anxiety for patients. Again, I, I think that treating if someone has pre existing depression is important to treat that. And I know people are reluctant to take medications for mental health saying, you know, because we all grew up in that era. Just have a stiff upper lip, pull yourself up by your bootstraps, everything is going to be fine. And, and that might

work for many people, but for people with Parkinson's, I, I would like people to remember that depression and anxiety are actually associated with real neurochemical changes in your brain. And so to trees that is really like taking a vitamin and if treating the depression and anxiety is not helpful, looking for the actual cause of the pain is important. And then applying the correct treatment for that type of pain is, is the next step.

Melani Dizon ([25:13](#)):

Let's see. Somebody said that they use magnesium. They started using magnesium for their pain especially for leg cramps and it's worked for them. And I think for those kinds of things, it's great. You know, talk to your doctor, obviously talk to anybody that is prescribing medicine and say, here's, you know, I'd like to give this a try. Like, what do you think? That's okay. And have them talk to you about it. I I don't have Parkinson's, but I have just tremendous leg cramps every night. And I have tried every possible thing that there is. And I think for some people it's just magnesium might do the track. Magnesium might be the greatest thing. Pickle juice might work for other people. So I think it's really great to experiment, but just make sure that you're talking to your doctor about whatever you're planning on trying. And then talking about pain and sort of different treatments. We will get into more specifically about treatments, but people are saying, you know, they're using CBD. What has been your experience in your, in your practice of working with client patients with CBD oil?

Dr. Janis Miyasaki ([26:19](#)):

So CBD has definitely exploded in the last few years, particularly in my country, which has legalized it. So it doesn't have to be medicinal. You can just go to your local shop and get whatever you want. And when we look at rigorous studies of pain, in fact, CBD is less effective than tricyclic antidepressants and might be slightly more effective than acetaminophen or ibuprofen and is less effective than antidepressants such as [inaudible]. So I think we have to take it with a grain of salt. A lot of people are attracted to it because they view it as natural. However aspirin is derived from winter green. So there are a lot of things that we use in a bit medicinal way that is produced by a pharmacy that actually started life as a natural compound. So I would like people to just realize as well that CBD can be

associated with changes in mood with hyperemesis syndrome, which can be very severe and lasts for months after the CBD has stopped.

That it can also be associated with lack of clarity of thinking and decreased motivation. And people with Parkinson's already tend to have more apathy and people without Parkinson's disease. And I think most spouses as their would say, the one thing that just drives them batty is, you know, trying to get their loved one to go to an exercise class. Because they hear this all the time now how important exercise is and socializing is. And if we are increasing apathy for patients, then really is that the right balance for some people, maybe it might be for other people it definitely is not. And so we have to keep that in mind. The other thing to keep in [inaudible] very in their purity. So when they took samples from stores around I think it was actually in Colorado they took samples from stores around Colorado. They found that almost all samples that were said to be pure CBD has some THC in it. And THC is the compound that we believe causes the psychiatric effects of cannabinoids.

Melani Dizon ([29:23](#)):

Great. so let's talk about, we talked about some of the other treatments, but what are some pharmacological specific treatments people want to know about DBS? How does DBS actually help with pain? And then some of the nonpharmacological treatments that you talk with more patients about. And then where does neuro palliative care fit in with this kind of treatment?

Dr. Janis Miyasaki ([29:52](#)):

So in terms of pain treatment, the principles are to start with what is called the pain ladder. So you always start with the least intensive, least side effect of giving a treatment. And those are the physical methods that I discussed using cold or heat and also stretching and flexibility. So helping people, particularly those who are less mobile tend to be very stiff and rigid. And if you move them around they will complain bitterly. I used to do that for my mother who had Lewy body dementia and I used to do range of motion and she would just, she would literally scream, you're killing me. And then afterwards she would say, Oh wow, I feel better. And every day we went through the same cycle. She never seemed to recall that she felt better afterwards. And, and so leaving the person to do the range of motion

exercises or flexibility themselves is often not successful in late stages because their perception is when you say raise your arms and they go like this, they say, yup, they're up. But then when you actually stretch them out, they can get further and they're, Oh, that's higher. So they don't actually perceive the amount of effort or the range of motion that they truly have.

Melani Dizon ([31:28](#)):

So quick question about your mom. So how long when she said, Oh, I feel better, how long did that last? Like through through a couple of hours throughout the day or

Dr. Janis Miyasaki ([31:38](#)):

It would last a couple of hours through the day. I have to say in the last week of life because her care got so burdensome, I just stopped doing it and I know she had more pain, but I just couldn't add another, I was working full time as a neurologist. This was just six years ago. I was working full time and working full time and coming home and doing it. I just couldn't, I didn't have the energy to do it. So I have a lot of empathy for the care partners and caregivers out there. It's we pile on all these things so that it's like, it seems like it's pages and pages of instructions of things to do. It's so hard to do. I understand that very much. Thank you.

Melani Dizon ([32:27](#)):

Okay, so we do the hot, the cold, the stretching, the least sort of invasive methods first

Dr. Janis Miyasaki ([32:35](#)):

And then the acetaminophen and the ibuprofen. Then you get to stronger nonsteroidal antiinflammatories like the Naproxin or Aleve that was mentioned. And then we moved to antidepressants or medications that might have antidepressant activities like Tramadol, Tramacet, Duloxetine, and tricyclic antidepressants, which is kind of difficult to use in Parkinson's because it might cause confusion. I and my cause too much sedation, but those are very effective medications for pain in general. Then we move on to anti epileptic medications that have been found to be effective or the treatment of pain. And this consists of Gabapentin and pregabalin. The reason why this is considered a higher level than

the antidepressants is because they can cause sedation and that dose is high enough to relieve pain, might also cause unsteadiness and increase the risk of falls where patients and then then we get to opioids at the top of the level.

I would say that if your pain has not been relieved by all these subsequent steps, that if your physician recommends opioids to try the smallest dose possible, and some of my patients have had very striking response at doses that our palliative care colleagues really would not consider effective. And there are frequently surprised at what a small dose can do for our patients. And this can make a tremendous impact on your quality of life. Once you have good control of your pain, please don't stop your medications. This is very common that someone will say, Oh, I feel good and why am I taking this pill? They'll stop it. And then a week later they'll call and say and screaming, I'm in pain. And the whole problem was they stopped their pain medication,

Melani Dizon ([34:54](#)):

Right? For the hope for the opioids. Is that something that then you kind of think, well, I'm probably going to be on this for the duration of my Parkinson's because, you know, we found it and it's working. Is it something where you said this lower dose that it's pretty surprising is this, can they stay on a low dose for a long time?

Dr. Janis Miyasaki ([35:16](#)):

Surprising thing with people with Parkinson's is they manage on a very small dose. So when oxycodone could be cut into portions I took the smallest dose, had the patient cut it into quarters, they took one quarter twice a day and they had a remarkable benefit from, I have so much pain, I want to throw myself off the balcony to no pain. Wow. And I think the striking thing about that was the palliative care, my palliative care colleague who was seeing the patient at the same time pot that's never going to work. And that way it worked. He was like, Oh my God, I'm so surprised. And so I think that this speaks to the pain in Parkinson's might be different. Also the people tend to be quite a bit older. So the patients that he is often treating, our palliative care specialists are often cancer patients. Now they are branching out to congestive heart failure and kidney disease patients, but many of them are still unfamiliar with neurodegenerative illnesses. And so even a palliative care Dr. May prescribe too high a dose because it's based on their

experience with cancer patients. So starting at the teeniest tiniest dose and then gradually increasing can be effective.

Melani Dizon ([36:48](#)):

So you develop the first neurologist led palliative care program in the world. Can you talk to us a little bit about what did that look like and for somebody with Parkinson's, maybe they've been newly diagnosed or have had a few years, like what would it, what would something like that look like for them?

Dr. Janis Miyasaki ([37:08](#)):

So, I would say in general that most patients who require neuro palliative care are in the later stages of illness. Mainly because of a lack of person power in palliative care. There are very few palliative care physicians in the world and there are very few.

Melani Dizon ([37:29](#)):

I'm sorry. How would you characterize, for the audience, how would you characterize the later stages? What are some things that are sort of indicative of, of that phase?

Dr. Janis Miyasaki ([37:44](#)):

So I would call the later stages someone who is requiring a walking aid. So typically someone using a walker and someone who, or someone who actually is wheelchair bound or has significant swallowing problems. And so there are some patients who within the first two years of diagnosis feel that they are palliative and they just want to be palliative. And the reality is that we want to use the best resources at the right time for the right person. And what our clinic has targeted and many clinics have targeted is people with unaddressed symptoms and people who have couples or families where there is caregiver burnout and specifically when they have pain as a significant problem we will address for a short term existential distress. But ongoing needs for psychotherapy are likely not best met in a neuro palliative care setting. So people who have had lifelong depression should continue with their mental health professional in the community.

And if they need assistance or input, they can call the psychiatrist attached to the movement disorder center or to a neurologist that they see for advice and tips on things that seem to be helpful. But requiring ongoing neuro palliative care needs is, is likely not possible. I would say that the number of centers that actually provide true new neuro palliative care are very limited. There's probably less than five in America that truly provide neuro palliative care. Many people say they do it, but they are not closely linked with a palliative care specialist and the re in my experience I feel that this is essential before you call yourself a neuro palliative care clinic because the neuro pal, the palliative care specialist has a very specific set of skills. They are so skilled at pain treatment, end of life care, having difficult conversations and being able to manage challenging family dynamics for a neurologist.

The neurologist has all this content expertise about what is a movement disorder, how to treat it, how to problem solve around it. But those expertise that the palliative care specialists has really are not part of a typical neurologist toolkit. So either the neuro palliative care program has to be led by a neurologist who has palliative care certification or a neurologist, palliative care physician dyad so that the team is working together to address patient needs. In my clinic, I have always had a spiritual care provider. And that is because it's not about religion. It's about the questions of why has this happened to me? How can I be hopeful and how can I move forward as well as addressing the care partner or caregiver distress over the change in dynamics, the change in roles and and lessening guilt, which is a significant challenge. Right.

Melani Dizon ([41:38](#)):

So when people come to your clinic, you're going to see this person and then you have a plan and then you have a general followup plan that these people are gonna see you every few months, couple of months, and they're just being monitored by more people.

Dr. Janis Miyasaki ([41:57](#)):

So we have a number of different followup plans. One is for some patients they just require one consultation and they are sent back to their neurologist and we'll, we're happy to see them again. For other patients. They are very comfortable with

their neurologist or family medicine specialist and they're happy to continue in that manner and see us as they need. And then for occasional patients who we feel they may require either a palliative home care or an inpatient admission to a palliative care service we will see those patients more frequently.

Melani Dizon ([42:43](#)):

So I'm going to go through, some of these questions are getting close to the end, so I just want to make sure that we get through some of these. So once somebody asked, is shortness of breath a symptom of Parkinson's and therefore makes exercise more difficult? Is that the case? That shortness of breath is a symptoms of Parkinson's,

Dr. Janis Miyasaki ([43:03](#)):

Shortness of breath can be a symptom of Parkinson's. And once again, I think you have to be checked by your family doctor to make sure that there aren't any cardiac or lung issues that are causing this. And if you have been checked, then the probable conclusion is that this is from your Parkinson's. Once again, it tends to be related to wearing off of the medication. And many patients actually experienced significant anxiety at the same time that they have this shortness of breath. Again, speaking to that, it's a wearing off non motor fluctuation symptom. And so trying to keep the person more on but more importantly trying to address anxiety and if there are any cognitive issues to address those symptoms first to see if that can relieve some of the shortness of breath into.

Melani Dizon ([44:06](#)):

So somebody was talking about how the spasms in their legs are really, really bad and they took their medication a long time ago and now it's so bad and they're not supposed to take it again for awhile, but they're so terrible they can barely move around. So to me this would seem like a conversation immediately with their doctor to say can we bump it up? Hopefully so that their meds can they're not waiting so long in between taking meds so they could maybe help with this pain or as you said you know, it might be a situation where there are other types of drugs they could be using.

Dr. Janis Miyasaki ([44:44](#)):

Yeah. One treatment that I didn't mention a specific for Parkinson's is botulinum toxin. So botulinum toxin can be very effective if someone is having repeated dystonic pain. And however people have to recognize that it weakens the muscle. That is his job is to weaken muscles. And so if you get an injection in your leg, it might, we can, it might get rid of the dystonia, but it might also weaken the muscles so that you notice it when you were doing other activities. But this is probably an underutilized treatment for pain in Parkinson's disease.

Melani Dizon ([45:24](#)):

So when somebody does come in for an injection, how long will something like that last? If they have, you know, let's say they have chronic dystonia and well not chronic, not all the time, but it's a regular occurrence for them and they come in and get an injection. What's the life of that?

Dr. Janis Miyasaki ([45:40](#)):

So many patients will have onsite a benefit within one to two weeks and the duration of benefit is approximately three months. Then SMEEs that they have to have the injections done every three months. So it's not a onetime deal.

Melani Dizon ([45:55](#)):

But is it a one time injection when you start and it can last for three minutes and you come and get another one? Or is it like a series of injections?

Dr. Janis Miyasaki ([46:01](#)):

Generally people should be injected only every three months because if you inject less frequently I would say probably every 10 weeks would be the least amount that you can do. But people who get small amounts of injections, multiple every few weeks are more likely to develop tolerance to the botulinum toxin because it's as if you're being vaccinated against it.

Melani Dizon ([46:25](#)):

Okay. somebody, because somebody had asked earlier about lidocaine patches how are those, do those work well? Have you found in your practice that those work well for people who are experiencing cramps and stuff like that?

Dr. Janis Miyasaki ([46:39](#)):

I have not actually tried lidocaine patches.

Melani Dizon ([46:43](#)):

Okay. Sorry, we don't have an answer for that one. Let's see. A couple of people said, you know, they have DBS and they're, they're feeling great. And no, no problems at this point. And then a couple of people are asking, you know, like one is a good time to look into DBS for something like this.

Dr. Janis Miyasaki ([47:04](#)):

Probably before the patient thinks it is.

Melani Dizon ([47:07](#)):

It's so confusing, right? Cause they were told, oh, this is the last chance and now it's definitely not that situation.

Dr. Janis Miyasaki ([47:16](#)):

I'm not sure that I've ever heard this is the last chance, but and then it changes because the criteria for deep brain stimulation is that you have still a good response to Levodopa deep brain stimulation does not improve beyond the best response to levodopa. That's the first thing people need to be aware of. And many, even neurologists, they will. Then what I do is a while. The reason why is it, it, the maximum benefit is no better than the maximum benefit from Levodopa. That's why we need patients to respond to it. But the deep brain stimulation means that the off time is less severe and shorter. Also if you have dyskinesia as as a bothersome symptom or painful dystonia that is a significant and disabling, those would be other target symptoms. And the time to consider deep brain stimulation is in fact when you have those symptoms and you're still functioning okay, but you're noticing is starting to impair your ability to function and you are cognitively relatively normal. So the biggest pitfall we find is that patients wait until well into their seventies and at that time, just in general aging people are already starting to have memory problems.

But then you add on top of that you have a neurologic progressive condition, then you are more likely to have cognitive problems. And the reason why we don't want to do brain surgery or someone who has cognitive problems is that we know that these patients tend to benefit less from the deep brain stimulation and they tend to have more cognitive problems after. And so any intervention that we do, we are trying to maximize your benefit and reduce your risk as much as possible. So the communist line I hear from people who refused deep brain stimulation is, I'll tell you when I'm ready. And often when the neurologist initiates this conversation it's because they feel the patient is actually ready to have surgery, has the appropriate target symptoms. And they're concerned that either they're getting to an age where they will tolerate the surgery less well, and there is good research to show that people over the age of 70 actually get less benefit and have more risk.

And that we're concerned about cognitive status because particularly for highly educated people, they look great for a long period of time and that when they start to decline, they can decline very quickly because they have this much reserve and they've gone through it. So they're still behaving normally and talking normally and thinking normally, but they've gone through all this super duper intelligent reserve, they've gone through it and now they're going to really decline much faster. Whereas someone who has not had the same education opportunities, the same career opportunities, they often tend to decline a little more slowly like this. And we can follow that with general screening tests.

Melani Dizon ([50:58](#)):

Great. Thank you. Well, we are just about out of time. I would love for you to just share maybe three actions that people can take every single day to minimize or in an ideal world eliminate pain. What are, what are three things?

Dr. Janis Miyasaki ([51:19](#)):

Well, Buddhist would say that living is a painful condition. And so not to make light of that it is, you know, we're all going to experience pain of some kind in our life. It's how we respond to it and what we can do to mitigate it or reduce it. And so I think some of the things we've talked about is one, taking your medications regularly. I cannot emphasize enough. We did get a chance to talk about this. Have a daily bowel movement because of course, if you have a daily bowel movement,

your medications work better. And if your medications work better, you're more likely to have a smooth response throughout the day.

And addressing any mental health issues. So many of our patients experience anxiety and depression and sleep disruption, all of those things will reduce your ability to face pain or face the challenges of having a chronic medical illness. So we want to address those things as well. And finally to not just count everything to your Parkinson's. So I can't tell you the number of times I've heard the most bizarre symptoms and the poor patient was told, Oh, that's from your Parkinson's. No, that is not from your Parkinson's. So to make sure that your primary care physician actually is open enough to think of other diagnoses when you present with pain or discomfort.

Melani Dizon ([53:04](#)):

All right. Thank you very much. I really appreciate you being here. I know everybody got so much value from listening to you. This is a topic that we hear a lot about and people have a lot of confusion and frustration around what to do about it. So hopefully this will give people tools and recommendations to talk to their doctors about and we'll be able to, some ways to help minimize some of the pain that everyone's feeling. So thank you so much for being here and to everybody on the call.

Dr. Janis Miyasaki ([53:49](#)):

Thank you.

Melani Dizon ([53:50](#)):

Thank you. Thanks. Bye everybody.