Solutions to Managing Spasticity in Kids and Adults

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[00:00:00] **Roberta Pesce:** For our next talk I am joined by Dr. Jacqueline Nicholas, a board-certified neurologist specializing in neuroimmunology who will be addressing spasticity and how it relates to tone, along with management strategies that can be used. Hi, Dr. Nicholas, welcome. Over to you.

[00:00:22] **Dr. Jacqueline Nicholas:** Hi, thanks so much, Roberta, and thanks to the SRNA for planning this wonderful symposium and for the invitation to speak to all of you. So, I'm really happy to be here with you on this beautiful fall day to talk about spasticity. Certainly, spasticity is a very common symptom that we see in individuals with rare neuroimmune conditions. And when I initially did my training in neuroimmunology I had no idea about all of the options that were out there, and as I started off, I became saddened by some of the people who would just take medications and feel very tired, and not feel like they could really move, or experienced a lot of pain from the stiffness that they had from their disease. And it was soon after that that I had the opportunity to do a fellowship with one of our physical medicine and rehab doctors at Ohio State to learn more about how to manage spasticity, and so now it's one of the things that I'm most passionate about in addition to treating the neuroimmune diseases. So, I'm really excited to walk through this with you and share with you some options that we have for treating this problem. So here are some of my disclosures.

[00:01:43] So what is spasticity? Well, it's really just a fancy word for muscle stiffness. So, we know that typically when we want to contract a muscle, such as flexing our bicep, really our tricep, the opposite muscle, should relax, and the bicep should contract, but when people have spasticity, and it can be anywhere in the body, oftentimes when they're trying to do one action, the opposite muscles are tightening up. And that shouldn't happen, but it occurs whenever somebody has had damage in the brain, or the spinal cord and many different muscles can contract at once. And not only can this be frustrating for trying to be mobile or do certain actions, but it also is a very big reason why people with these conditions can experience pain as a result of the muscle stiffness or spasms.

[00:02:36] So there actually are some advantages. So, if we think about it, if somebody had a damage in their brain or their spinal cord, and let's say that that led to weakness in one side of their body, if the let's say the right leg was weak, if it was so weak that somebody couldn't bear weight on it, they would have trouble with transfers, standing or even attempts at walking. And so sometimes spasticity can be helpful when muscles become weak after damage in the brain or spine because that stiffness can actually serve as a brace.

[00:03:15] So oftentimes when someone has spasticity, we want to be really careful to minimize pain and minimize the chance that somebody could become permanently stuck in that position, but we also want to use spasticity to our advantage if somebody has a lot of weakness, so it's a very careful balance. Now, we know that spasticity because it's contraction of the muscle it can also reduce shrinkage of the muscle. It can help to strengthen our bones and prevent fractures and as I mentioned, improve some of our activities of daily living. But there's certainly a lot of disadvantages. So many individuals will report that because of their spasticity, they have trouble with even simple things, like trying to go to the bathroom.

[00:03:59] I have patients who have spasticity in the muscles that bring their legs together, the inner thighs, and they'll say, "When I'm going to the bathroom it's really hard to actually clean myself afterwards because my legs want to stick together." And so, these are all really important things to talk to your doctor about because there are so many things that we can do to improve that for you. We talked about how it can impair mobility. Sometimes for people who can walk, we can see that they have kind of an inversion and turning in of their foot and when they walk, they're kind of walking right on the ball of the foot, or the toes, or even the outside of the foot, and that can lead to serious injuries to the joints, and also significant pain.

[00:04:43] So by treating spasticity we can loosen those muscles and help so that we're avoiding those long-term consequences. Now, we also talked about the pain that it can cause. If somebody has significant spasticity to where it limits mobility, it can actually increase the risk of pressure ulcers and orthopedic deformities. Because spasticity requires so much energy for that continuous muscle contraction, we can actually also see that people can have weight loss because they're expending a significant amount of calories, and we can also see sleep disturbance as well. Many people that experience spasticity report that it's worse at bedtime, and they feel like they're having spasms, or their legs are jerking, and certainly this can affect or mood and lead to worsening of depression and impair functional independence.

[00:05:39] Now, it's really important to note that there are some really key things that we can try to optimize to reduce spasticity. So anybody who is listening to this, if you have spasticity you may notice that if you're having a urinary tract infection that can actually increase spasticity, so one of the first things that I ask my patients if they feel like things have been going pretty well with what we're doing and that it's increasing is let's make sure there's not some type of urinary infection or other infection going on. Basically, any annoying stimulus to the body can increase spasticity. So often times in the cold weather, that's a time where spasticity can worsen, and sometimes what I'm doing for somebody's medical management of their spasticity in the summertime I may need to increase that in the wintertime.

[00:06:28] Certainly if somebody is having worsening mood of extreme emotions, that can worsen it. People sometimes tell me if they get really excited sometimes their leg will just jerk out and be stiff. We also want to make sure that there's not wounds in the skin, such as pressure ulcers, ingrown toenails, even tight clothes can increase spasticity, and then really pain anywhere or infection anywhere in the body. And a lot of people say that it just comes out when they're repositioning, and so that can be really challenging and frustrating when people are trying to move.

[00:07:04] So we want to make goals, and it's very different for every individual because everybody's degree of spasticity can be different, and sometimes even if somebody had an event happen 10 years ago, a transverse myelitis, they may not have noted that early on it was as much of a problem, but it may increase over time, and so we need to continually reassess those goals and make sure that we're meeting the needs of that individual. So, we want to make sure that we're minimizing spasticity to help as much as possible with activities of daily living.

[00:07:41] We want to make sure that somebody's mobile. We want to continue to manage that spasticity so they can be maintained that mobility. Certainly, we want to manage pain and discomfort, that is a key important factor of treatment of spasticity. And a very major complication is that if somebody has extreme spasticity they could actually get stuck in that position. So, I've had patients come into my clinic where their hand is just actually stuck like this, and that can be very hard to treat if the tendons are fused to the bones, and we call that contracture. So, we want to try to prevent that from happening so that somebody doesn't require a surgical fix for that issue. It can also, by reducing this, can help make it easier for loved ones and caregivers of an individual to help them do the things that they need to do, and it can make you even more successful in working with rehab, physical therapy, and occupational therapy.

[00:08:45] Now, I know this is a busy slide so bear with me here, but I wanted to make sure that we could talk about the fact that treatments are not always medications for this. So, some of the most important ways that we manage spasticity is actually employing a daily stretching program. And this can be challenging because certainly as our last speaker spoke about, fatigue is a big deal in rare neuroimmune conditions, and so stretching is important. And I tell my patients, even if you can just do it for a couple of minutes in the morning and a couple of minutes in the evening that's much better than not doing it at all. Certainly, exercise can help.

[00:09:26] Some people find massage beneficial for stiff muscles, but one of the most important things is physical and occupational therapy. They can help us to better understand the best ways to stretch these muscles, the best ways to walk or transfer when we have spasticity, and how to best optimize even the treatment that we're doing. So sometimes as I'm treating some of these spasticity, I'm also incorporating physical therapy, and we're giving each other feedback so that we can optimize the care of that individual. Some people benefit from casting of splinting, so where they actually wear splints around a joint where they're tight for a period of time throughout the day to continue to stretch those muscles.

[00:10:12] Now, the medication options most often start out with oral muscle relaxers, and I'm going to talk a little bit more about that in a second, but those types of medications you would obviously take by mouth and they can be helpful, but sometimes people can become very sleepy, they can have more fatigue and it can impair memory and thinking, so we have to be very careful about starting at a low dose and increasing up and making sure that we're not causing other problems in the mix. Now, if somebody has spasticity that's more focal, for instance if somebody comes in and they say, "Really what I'm bothered by is my arm wants to be close to my chest like this and I can't really extend my arm and my fingers are curling in." A lot of times using Botox injections, which I'll talk about more in a minute, can help to loosen that where somebody is a lot more comfortable.

[00:11:04] Sometimes if spasticity is very severe a physical may inject phenol or basically actually damage the nerve so that it isn't able to cause that muscle to contract. And then for severe spasticity, especially when it's prominent in the legs or throughout the entire body, something called intrathecal baclofen where liquid baclofen is given into the spinal fluid can help. There are many other options for more extreme situations like surgical options, and then certainly cannabinoids are being studied for the treatment of spasticity, and we have some early studies showing that even medication, inhaled THC CBD treatments are appearing to be beneficial for loosening muscles and we're trying to better understand the long-term side effects of that.

[00:11:59] So oral antispasmodics, these are the most common, this list here. Baclofen and tizanidine I would say are probably the most common that we use in the treatment of spasticity, but as you can see there are many, many options, and so the dosing varies based on the individual and based on the severity of their

spasticity. But we talked about sleepiness and tiredness and sometimes impaired cognition are the biggest side effects of these medications, but they can be helpful as night, especially when spasticity is waking somebody up because if it helps you to sleep it also relax muscles that can be very beneficial.

[00:12:35] This I just wanted to briefly show you. So, the American Academy of Neurology is the guideline recommender basically for all neurology care, and there is very strong evidence that botulinum toxin injections or Botox can help for people that have arm or leg spasticity, and so that's really exciting when we have that high level of evidence that this works. And I wanted to show you that there's not just one type of Botox, there are many different types. And physicians who are experts in spasticity may use different ones for different reasons. Or if one stops helping you where it had helped you for many years, it's possible that you've developed an immunity to it and we may need to switch to a different toxin, but that's the great thing that we have so many different options.

[00:13:24] I wanted to show you this image because this shows you the different positions that people can develop from spasticity. And you can see here that some of these folks have clenched wrists, or a bent elbow, or the thumb coming into the palm, and so we want to make sure that we're managing that early to prevent it from getting stuck that way. Certainly, in the legs, you can see that there is the bent knee where somebody has trouble getting it straight, but I have a lot of patients who tell me, "Gosh, when I try to get in and out of a car my leg sticks out straight and I can't get in and my spouse has to bend it really hard," and we can use Botox for these positions. Just wanted to remind you that there are several advantages. So, it gets injected directly into the muscle where it stiffs so we're avoiding that broad effect that we typically see with the oral medications where people get overly sleepy or can have drowsiness, cognitive fatigue.

[00:14:26] Now, there are some disadvantages. It typically lasts for about 3 months. Some people get a slightly longer benefit, so you would have to return to your doctor to receive these every 3 months. Because it is a needle there can be some pain with the injection, although many of my patients who benefit say it's not that bad, and we have some numbing sprays that we can use to minimize that. Sometimes there can be bruising, and then if somebody is given too much Botox it can actually make the muscles weaker, so we want to start a low dose and slowly increase. Within the Botox warning it says there is a rare risk of death from spread of the toxin effect. This is not something that I have ever seen in my entire career when we're injecting limbs, but if somebody were injecting high amounts or near the muscles of respiration or swallowing this would be a potential risk.

[00:15:20] Now, I want to mention to you intrathecal baclofen. So, this is when somebody has very severe spasticity in many muscles of the body and either there's not enough Botox that could actually be given to manage the spasticity or it's just so many muscles that this would really be the ideal way to address. And again, what we see is it's generally most effective for the legs rather than the arms. Now, you can see in this picture in the upper right-hand corner, this is what the pump looks like. It's basically the size of a hockey puck and typically goes in the lower abdomen. There is one that's for kids that's a smaller size and there is a larger adult size. And basically, that pump is full of liquid baclofen and then there's a tiny tube, all of this is implanted in the body where nobody could see from the outside that you had this device, and basically it allows for the continuous release of a very tiny amount of liquid baclofen to manage that spasticity.

[00:16:20] And I will tell you that many patients who have required this have really thought it was life changing, but it does require a big commitment because someone has to follow up. They have to get the baclofen changed out at the longest ever 6 months, if they use it more quickly it may be as frequent as every month to 2 months. And then the pump life is only about 7 years because it has a computer chip that's not guaranteed beyond that. So, this is a big decision, but for somebody with severe spasticity can really be life changing.

[00:16:52] So in conclusion, spasticity is very common in transverse myelitis and other neuroimmune conditions. If you think you're experiencing it, please talk to your doctor about it. There are so many things that we can do. Physical therapy, occupational therapy, stretching, the oral meds, Botox, intrathecal baclofen are proven ways to minimize spasticity, and it is key to improving quality of life. Thank you so much for your time today and I'll turn it back over to Roberta.

[00:17:24] **Roberta Pesce:** Yes, thank you so much, Dr. Nicholas, for this great talk that you just gave. We had one question pop up that might be interesting to address, "Can the feeling of being squeezed around the rib cage, AKA, also known as the MS Hug or like the Victorian corset, also be a symptom of other rare neuroimmune diagnoses, like MOG, TM, etc.?"

[00:17:46] **Dr. Jacqueline Nicholas:** You're exactly right. So that symptom really got the name MS Huge because I think it was first described in MS, but I do see it in my patients with NMO spectrum disorder, MOG, transverse myelitis, because really anybody who has had any damage in the spinal cord can feel that symptom of that tight band around the chest or abdomen.

[00:18:08] **Roberta Pesce:** Perfect. Yes, indeed. Well, thank you so much for your time. I think I'm ready to move on to the next speaker, but we're very grateful that you are with us today, I'm sure our community is as well. Thank you for your time, Dr. Nicholas.

[00:18:23] **Dr. Jacqueline Nicholas:** Thank you very much. Bye-bye.