

# Sexual Dysfunction and NMOSD

You can watch a video of this podcast at: [youtu.be/7CeFGGBPXCw](https://youtu.be/7CeFGGBPXCw)

[00:00:00] **Intro:** “ABCs of NMOSD” is an education podcast series to share knowledge about neuromyelitis optica spectrum disorder or NMOSD, a rare relapsing autoimmune disorder that preferentially causes inflammation in the optic nerves and spinal cord. “ABCs of NMOSD” podcast series is hosted by SRNA, the Siegel Rare Neuroimmune Association and in collaboration with the Sumaira Foundation for NMO, and Guthy-Jackson Charitable Foundation. This education series is made possible through a patient education grant from Horizon Therapeutics.

[00:00:58] **Krissy Dilger:** Hello and welcome to the “ABCs of NMOSD” podcast series. Today’s podcast is titled “Sexual Dysfunction and NMOSD.” My name is Krissy Dilger and I moderated this podcast. “ABCs of NMOSD” is made possible through a patient education grant from Horizon Therapeutics. Horizon is focused on the discovery, development, and commercialization of medicines that address critical needs for people impacted by rare autoimmune and severe inflammatory diseases. They apply scientific expertise and courage to bring clinically meaningful therapies to patients. Horizon believes science and compassion must work together to transform lives.

[00:01:45] For today’s podcast, we are pleased to be joined by Dr. Philippines Cabahug. Dr. Cabahug earned her BS in Physical Therapy at the University of the Philippines in 1994 and her medical degree at St. Luke’s WHQ Memorial, Philippines in 2000. She completed a Physical Medicine and Rehabilitation residency at the Philippine General Hospital in 2005. She was awarded a UN Merrick scholarship to pursue her postgraduate diploma in Gerontology and Geriatrics at the University of Malta in 2004. In 2009, she finished her internship in Internal Medicine at AtlantiCare Regional Medical Center in Atlantic City, New Jersey. She completed her second Physical Medicine and Rehabilitation residency in 2012 at Johns Hopkins Hospital and a fellowship in Spinal Cord Injury Medicine at Johns Hopkins Hospital/Kennedy Krieger Institute in 2013.

[00:02:47] Upon completion of her fellowship, Dr. Cabahug joined the International Center for Spinal Cord Injury as a full-time physician. She received her board certification in PM&R and in Spinal Cord Injury Medicine in 2013. She is the Director of Musculoskeletal Ultrasound at KKI. She runs two MSKUS clinics at KKI, a musculoskeletal diagnostic clinic and an ultrasound-guided intrathecal pump access clinic. Dr. Cabahug is actively involved in medical education as a Faculty Clinical Instructor with the Department of Physical Medicine and Rehabilitation at The Johns Hopkins School of Medicine. Welcome, and thank you for joining me today. Can you just begin by defining sexual dysfunction? Are there different types of sexual dysfunction?

[00:03:45] **Dr. Philippines Cabahug:** So, in a person who has had involvement of their spinal cord, either from trauma or from a disease like neuromyelitis optica or transverse myelitis, sexual function can be affected. It just depends on which part of the spinal cord is affected, meaning how high or how low in the cord. There are certain types of sexual dysfunction which sort of mirror your impairments or the loss of function when you have a spinal cord injury. So, if you have a really significant impairment in your cord, like from the neck going down, it’s very possible that with your sexual dysfunction, you are not able to experience arousal or

have abnormal, or decreased, or absence of sensation. It could also present as the inability for males to have an erection or ejaculation. And for females, it's also possible that the sexual dysfunction can present as either decreased, abnormal, or absence of sensation in the vaginal area or the vulva area, or they could also have decreased arousal in terms of they don't get lubricated. Normally, when a female is aroused, then we have some vaginal lubrication, but that might be affected when you have a disease or process that affects your spinal cord.

[00:05:15] **Krissy Dilger:** Thank you. So, jumping right in, you mentioned arousal problems for men and women. How are these treated in your clinic for men and for women?

[00:05:30] **Dr. Philippines Cabahug:** So that's actually a good question and that might be a long answer. So, I have to backtrack a little bit because there are different types of arousal. And again, the type of arousal that you'll have intact depends on what part of the spinal cord or how high up in the spinal cord that you're affected. So, in a person who - so let me backtrack, you have what's called a psychogenic arousal, wherein you have your mind and body get sexually excited, and it's because of what's going on in your brain.

[00:06:04] Remember, the brain is one of the biggest sex organs, so that psychogenic arousal you get, the body and the mind gets excited from a thought, an idea versus a reflex arousal, you have to physically touch or stimulate in order to be aroused. So that's psychogenic, all in the mind. And then reflex, meaning physical stimulation of your sexual organs, either breast or the genitalia for that matter.

[00:06:32] Now, for psychogenic arousal, if you have a spinal cord injury, that's from your chest up from T10 up, your ability to be excited by thought may be affected. So, if you think or - so if you see a picture of Brad Pitt, then you're not going to be excited. So, you'll lose your psychogenic arousal, and you'll have to self-stimulate. So that's if you have a high enough level, you'll lose your psychogenic arousal.

[00:07:07] If the level is very low, in the sacral, the part of the cord that supplies your sacral area, then that's more challenging, you will not be able to self-stimulate yourself into arousal. And then there's this in between land wherein you may have those types of arousal, the psychogenic and the reflex arousal, but they're not working well together. They're not at their optimal, they're not coordinating well with each other. So hopefully, I got the basics of the types of arousal and where in the spinal cord you can get affected.

[00:07:52] Now, in terms of treatment, so that's a tricky part because there's no one size fits all treatment. It will again, depend on how you've been affected. For those who lost or have an impairment in the psychogenic arousal, good news is there's still reflex arousal. So, they can self-stimulate. And then for those who lost that reflex arousal, we can try other tricks or compensatory techniques like discovering other erogenous zones in the body that you might not have thought would be very exciting.

[00:08:33] I have some patients who report that they get excited or stimulated when they are - with kissing because that becomes their next erogenous zone already. So, those are one of the few things, at least for arousal. Erection, ejaculation, etc., it's another, different matter. For women, for example, to help facilitate if they are able to - if they have some sensation and they can derive some pleasure from self-stimulation or it's decreased. Lately, there are now vacuum devices that can be applied over the clitoris to help with that in terms of stimulation. For men, there's vibration devices that can also help with some pleasure - to help them feel some pleasure or it can help them with erection, ejaculation too.

[00:09:32] **Krissy Dilger:** Okay, great. Thank you. You said NMOSD can affect sensation during intercourse, and you just mentioned some of the treatments for if it does affect sensation. Is there anything else you wanted to add about treatment for that, or is there anything besides medication or these devices people can do?

[00:09:57] **Dr. Philippines Cabahug:** So, first of all, in terms of - I'd like to try to approach things holistically because sexual health is not just the physical aspect, but it's also the mental aspect as well. I counsel my patients and I talk with them if this is something that they are ready for, there's also that aspect I talk about with them, what are their concerns. And this is something that I would advise your listeners out there and the members of the SRNAs community. Don't be afraid to ask questions with your providers regarding the topic of sex because you don't know what you don't know, and they won't know how to counsel you unless you ask.

[00:10:43] One of the things that's also important is making sure that your overall health is good. Obviously, if you're not in good health, you'll not be able to focus on enjoying this intimate act. I also would counsel on making sure that your bowel and your bladder program is really very good and well controlled because one of the challenges is it can be a buzzkill if you're always worried about if you're going to soil yourself. I tell my patients, though it does take some spontaneity out of having sex or being intimate with your loved ones, make sure that you've done your bladder and your bowel program, you've emptied your bladder or bowel so that you can focus on enjoying the moment and being in the moment.

[00:11:43] Another thing to consider is some of our patients will have significant spasticity. So, it's really important to have that spasticity well managed. For example, in females, if the hip adductors are very spastic, I mean, just doing the act of sex might trigger the legs to just slam shut. So that's going to be a challenge. So, they can talk with their providers about medicines to help with their spasticity. Some of them get Botox injections through those specific muscles so that it's not going to slam shut if the spasticity gets triggered. And it all depends on how badly the cord was affected, how involved the cord is.

[00:12:28] There are generalized patterns but not everyone presents the same. Some people have more numbness. Some people have more tingling and burning. Some people will not have sensation at all. So, those are the things that we usually see. It's either they have decreased sensation, abnormal sensation, or no sensation.

[00:12:53] **Krissy Dilger:** Thank you. And for people who have their mobility affected by their NMOSD, how can this affect sexual function?

[00:13:05] **Dr. Philippines Cabahug:** Positioning is one big thing that comes across immediately to my mind. Again, it's going to be a challenge. The good news is the missionary position is not the only position for sex. There are other positions that are available. Your female partner can be on top instead of the usual missionary position. If you go on the Desire website, there is this pamphlet called "Pleasure Able," which is a booklet which has a lot of information regarding sex toys, positions, adaptive devices for people with impairments to be able to have sex.

[00:14:00] **Krissy Dilger:** Thank you.

[00:14:02] **Dr. Philippines Cabahug:** One more thing before I forget - sorry, I did mention spontaneity might be affected because sometimes you have to plan your day. Same thing with positioning. You have to make sure that positioning is appropriate. You have the space to do this, to have sex.

[00:14:37] **Krissy Dilger:** Got it. Thank you. And then we get a lot of questions also about fertility for both men and women. So can NMOSD affect fertility?

[00:14:51] **Dr. Philippines Cabahug:** In general, for females unless you have another problem, your fertility should not be affected. In males, traditionally, those who've had significant spinal cord injuries, spinal cord disease, sperm motility may be affected, or sperm quality may be affected. I think the biggest challenge is if

your sexual dysfunction involves you not being able to have an erection or ejaculation. That's going to affect how you're going to have children. So, that's also one aspect. The first one is the quality of your sperm and the motility of your sperm, and then the other one is actually getting to have an ejaculation. So that's how it can potentially be affected.

[00:15:43] **Krissy Dilger:** Thank you. And then, are there pelvic floor exercises or any kind of physical rehabilitation that can improve sexual dysfunction in people who have been affected?

[00:15:59] **Dr. Philippines Cabahug:** So that's actually a good question. Again, I'm going to go back to my earlier statement. It depends on how involved your cord has been. So, if somebody has a complete spinal cord injury, meaning they're completely paralyzed, no sensation, no function, I do not think that pelvic floor therapy will help. Pelvic floor therapy is actually more helpful in those with what we call incomplete injuries, meaning having some control, some sensation, but it's not always true.

[00:16:36] There are limited studies in people with spinal cord injury regarding pelvic floor exercises in order to help with sexual function. That being said, I'm not against trying it. Again, as long as you have some function and control, there is a higher chance that it might help, or it might work. If it's not for your sexual function, it may help with bladder or bowel. But if you are one of those who have the complete injury, it's highly unlikely.

[00:17:09] **Krissy Dilger:** Got it. Thank you. And then if somebody is experiencing sexual dysfunction, how can they get evaluated by a health care provider? Who should they see? A neurologist or urologist? Just any advice you have for someone experiencing these issues.

[00:17:27] **Dr. Philippines Cabahug:** Always for males, it's very important that they see a urologist and it's going to be a challenge to find somebody who knows specifically about NMO. So, my advice is for males to see a fertility specialist or urologist, who knows how to treat patients with spinal cord injury because if you're just say NMO, they might not recognize what it is. But if it's a spinal cord injury, you'll have a bigger pool. For females, also the same thing, you see a gynecologist. It's a little bit easier with females because there are a lot of OB gynecologists who are comfortable or have had experience in dealing with women with paralysis.

[00:18:24] **Krissy Dilger:** Got it. Thank you. I think that's all the questions I had but was there anything else you wanted to add about sexual dysfunction or any final thoughts?

[00:18:37] **Dr. Philippines Cabahug:** Talking about sex is always difficult for patients and families, and even sometimes for the providers but what I want to impart to the audience is that sex is a normal part of the human experience. It is something that you have a right to. Hence, it is important that if you have questions about it, please do not be afraid to ask your provider.

[00:19:08] **Krissy Dilger:** I think that's great advice. We're so thankful for you to have joined us today and volunteered your time and your expertise. Hopefully, we can continue this conversation and talk more in the future.

[00:19:24] **Dr. Philippines Cabahug:** Thank you so much. It's been a privilege to be part of your community.

[00:19:29] **Krissy Dilger:** Thank you.