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Empowering Patients with CIDP: Education, Support, and Personalized Care Strategies

Mr. Quigley:
You're listening to *On the Frontlines of CIDP* on ReachMD. I'm Ryan Quigley, and today I'm joined by Danielle Minetti to discuss how clinicians can better empower patients with chronic inflammatory demyelinating polyradiculoneuropathy, or CIDP. Ms. Minetti is a clinical nurse educator and the creator of Lucid Med, an online platform focusing on chronic illness education. Ms. Minetti, it's a pleasure having you on the program today.

Ms. Minetti:
Thank you so much for having me. I'm really excited to talk about this. It's one of my passions. I have many patients with CIDP.

Mr. Quigley:
Absolutely. Likewise, it's a pleasure to have you with us. To start us off, what are some of the more common misunderstandings patients have when they're newly diagnosed with CIDP, and how can clinicians address those misunderstandings or concerns?

Ms. Minetti:
One of the most common things that I've seen historically is newly diagnosed patients often don't understand the distinction between a vaguely defined peripheral neuropathy versus what CIDP actually is. And with that, they'll fall into one of three mindsets, the first being the ones that want to minimize what this is. So they'll think, "This is just some tingling. I'll take a pill, and I'll be fine, even though my doctor seems to want to treat it really aggressively." They don't quite understand that it's an active immune process. But on the flipside, we'll also see some patients that hear the word "chronic" or "progressive," which is true, but they'll immediately assume the worst-case scenario—that they're going to wind up in a wheelchair and there's no way to stop that. And then the final is those that deny. They don't really want to buy into the autoimmune angle at all. Maybe they had a back injury or a car accident, and they're more convinced it's a mechanical issue, so those areas right there are the most common misunderstandings and misconceptions that I tend to see.

The way to address this as providers is that we need to identify which mindset they're in. Really, that's the starting point—and the barriers to understanding what this is and then meeting them exactly where they're at. For example, maybe you have somebody who's done a fair amount of research, and they have a really good baseline. Those patients are easier to educate. But then there's patients who just know that their feet are tingling and they're tripping a lot more than usual. So bridging those gaps is important and trying to identify what struggles they might have upfront is important for providers in that respect.

Mr. Quigley:
So on that note, what educational approaches have you found most effective when helping patients and their families learn more about CIDP?

Ms. Minetti:
Well, education is huge, and this will harken back to really knowing our patients. That's really where it starts. Patients take different approaches. Some will have already researched the condition and know everything, but I always start by asking them what they already know about CIDP, if anything. I never assume because most people will leave their doctor's office and forget everything that they were told. I'll also ask what sources of information they are most comfortable with. Are they better with written material versus video format? What do they tend to reach for first when they're looking for this type of information? Though, really, regardless of what they say, most will prefer having a dialogue where they can take notes and have a family member listen in. I like to use analogies as well. This is a huge one—relating nerve anatomy to basic electrical wiring. It just makes it easier to visualize. Many don't know what the parts of a

nerve are, but everyone pretty much knows what a wire looks like and how it functions.

One of the other things that I put into practice when I'm teaching somebody—and I found this has made a huge difference—as clinicians, we were taught to see one, do one, teach one. That's how we learned. So in terms of that, the first part of it—the see one—is helping them understand it, pulling back the curtain on the heavy clinical terminology and explanations, and painting that picture using visual aids or simple analogies, diagrams, or anything that helps them understand the process and the pathology in a way that's really meaningful to them. And then from this vantage point, we can segue into, "Here's how it's specifically affecting you personally. This CIDP process that's going on here is causing this symptom." So I find that is really helpful because a lot of people, when they learn about CIDP, it tends to be all the information out there that's thrown at them and floating around in the ether. But helping them personalize it to themselves really goes a long way. And then the last part of it is I actually have them teach it back to me. Not all patients are going to need this in-depth type of education—most will suffice with just a general explanation—but for somebody who is, those are the key areas that I find very important.

Mr. Quigley:
For those just tuning in, you're listening to *On the Frontlines of CIDP* on ReachMD. I'm Ryan Quigley, and I'm speaking with Ms. Danielle Minetti about how we can better engage with patients with CIDP.

So, Ms. Minetti, I'd like to zero in on best practices for helping patients navigate their treatment options. How do you support patients in making informed choices?

Ms. Minetti:
It really has to be something that is important to them because if somebody feels like they're being pushed towards a therapy due to everybody talking about the urgency and stopping the progression of a condition like CIDP, a lot of people don't like that pressure, and they wind up not staying on therapy if they felt that. So, again, I come back to meeting them where they're at emotionally, cognitively, spiritually, and functionally. So even if they've had symptoms for a while, it's important to remember and not lose sight of the fact that it's never easy to learn that you definitively have this condition. So some patients want all the data, the clinical trials, and the side effects. Some want all of it. Others just want to know when they'll be able to hold their grandchild again and find consistent relief.

So I really tailor the conversation to the individual. I'll walk them through risks, benefits, and what the day-to-day might look like on different therapies for them. I find that the more I can involve them in this, the more they internalize it and make choices that align with what we know works best to treat CIDP, because otherwise, it's not going to stick. I'll ask them how CIDP is impacting their daily lives and if things were to remain unchanged, what would that look like versus if they had true improvement? So these are all important questions and different ways to approach it, but informed choice is really important with any therapy, and this condition can sometimes come out of left field for people.

Mr. Quigley:
Now, you mentioned how treatment is really tailor made to the individual. What about nonpharmacologic strategies? And how can we help patients integrate supportive care into their specific daily lives?

Ms. Minetti:
Non-pharm support is critical in the general medical management of CIDP because our nerves have the ability to heal and rewire in many cases, but supporting the nerves, in this is really multifaceted. Physical therapy helps with flexibility and strengthening and retraining the nerves back. Occupational therapy helps with activities of daily living that might have been impacted prior to treatment and helping them gain some independence back and feel a little steadier with things. Counseling is another big one. A lot of people struggle—especially the younger people that are coming out of the woodwork with this—since COVID, we've seen a rise in this in much younger people—so, in that respect, tailoring the conversation is really very important. They're readily aware and willing to do counseling, whereas some older patients might not be, so it comes down to knowing your patients. But nonpharmacological management is absolutely key.

Mr. Quigley:
Now, of course, we're living in a world where technology is very much intertwined with care for patients with a plethora of different disease states. Are there any digital resources you would recommend sharing with patients who have CIDP?

Ms. Minetti:
I usually will point any patient that comes across my desk to the GBS/CIDP Foundation International, and the reason I like this website is because it is really geared towards someone who is newly diagnosed. It has something for everyone depending on where they are, but the newly diagnosed education is really done well. It's pretty simplified and broken down, and I like this because everything's in one place. It's got support group connections, videos they can watch, and literature, so I like that.

The other side of it is sometimes people, with all the meds they wind up taking, can get brain fog, and they can have a hard time tracking that and managing it. So I also will refer patients to CareClinic, which is an online or digital way to manage their therapy, their therapy appointments, and their medications. They can track their symptoms, so it's a really nice tool for them to use.

And then the last one is if they're looking for digestible information—on YouTube if they're tech savvy—I'll send them to Lucid Med and Lucid Med Hub. Because sometimes patients will leave a doctor's office and feel under the pressure of the clock, and maybe they won't ask the questions that they wanted to, so when they can educate themselves in the comfort and the pace of their own home, I find that information sinks in better. So that's also another great resource—both of those sites.

Mr. Quigley:
And finally, Ms. Minetti, do you have any key takeaways that you'd like to share with our audience before we close?

Ms. Minetti:
CIDP is definitely not one-size-fits-all. I think that's the overarching theme of what we've talked about. A lot of people will go years before they get a diagnosis, which is the unfortunate part of this condition, so if you have a patient advocating for themselves, then really try and be cognizant of that. Spend time if you can explaining things to them. And I also find and highly suggest that providers can have some sort of prepared sheet—a fact sheet where they have those resources listed rather than just handing them a pamphlet. Most of those people aren't going to read a pamphlet. They would rather talk to somebody or watch a video or read a book. It shows that they put some thought into it for patients who are newly diagnosed—that handholds them a little bit through that. Because CIDP can vary in so many ways, having something spelled out for them will really go a long way in helping them manage it and get out of the starting gate because it can be very daunting for most.

Mr. Quigley:
With those final thoughts in mind, I want to thank my guest, Ms. Danielle Minetti, for joining me to discuss how we can better support patients with CIDP. Ms. Minetti, it was awesome having you on the program today.

Ms. Minetti:
Thank you for having me. Always happy to talk about CIDP.

Mr. Quigley:
For ReachMD, I'm Ryan Quigley. To access this and other episodes in our series, visit *On the Frontlines of CIDP* on ReachMD.com, where you can Be Part of the Knowledge. Thanks for listening.