

For Wieneke, Post COVID Syndrome includes multiple neurological issues

By Julie Buntjer
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ADRIAN — Four months after Jolene Wieneke was officially diagnosed with Post COVID Syndrome by the Mayo Clinic in Rochester, she's still searching for solutions to some of the lingering side effects from having contracted the virus last November.

Wieneke had to take short-term disability from her job at Citibank in Sioux Falls, South Dakota last December. While she's returned to work, she's still not able to complete an eight-hour day on the job.

Back in February, when Wieneke first shared her story with The Globe, she was dealing with fatigue, tachycardia (fast heart rate), brain fog, headaches, dizziness, blurred vision, insomnia, neurological issues and tingling sensations. She was scheduled to go through three days of testing at Mayo a week later, and ended up getting called back for another round of testing the following week.

Doctors have since informed Wieneke she has Central Sensitization, which impacted her brain and spinal cord. It's the driving force behind her shortness of breath, brain fog and sensory sensitivities, including vision and hearing problems. Abnormal results in her autonomic reflex test confirmed her autonomic nervous system doesn't function properly.

"The autonomic nervous system controls heart rate, blood pressure, breathing, digestion, body and skin temperature, hormonal functions, bladder function, sexual function and many other functions," Wieneke shared in an email. "My Dysautonomia symptoms include heart rate issues, both tachycardia and low heart rate.

"I have blood pressure regulation issues, breathing issues (both central apnea and shortness of breath)," she added. "I have bladder issues and digestion issues. I also

have Sudomotor neuropathy, which causes heat intolerance and other sweating abnormalities. Also, my toes are a 'lovely' shade of blue/purple (called COVID toes), meaning there is some damage to my vascular system somewhere."

Wieneke said she had some issues with each of her two COVID-19 vaccination doses, but noted that reaction to medications is typical for her. She said once those issues cleared up, she actually felt good — wonderful, in fact. She was able to walk a 5K, and noticed less fatigue.

Now, however, the tiredness is returning, and Wieneke said she's relapsed.

In May, Wieneke traveled to the Mayo Clinic for vision testing and learned her blurry vision and light sensitivity is permanent unless her brain can find a new pathway to react to stimuli.

With so many different issues — including some new problems — she continues to endure the long haul.

"You might wake up with something; you might have something in the middle of the day," she said. "You might have a good day and people see you out and about, but that doesn't mean you'll feel fine the next second. That's what's hard about it."

Wieneke's latest Post COVID Syndrome problems include internal tremors that go across her abdomen and down her left arm. The tremors started waking her up at night about a month ago, and as of last week, she was feeling them all the time. Doctors say it's another neurological result from having the virus.

Lack of treatment options

With her diagnosis of Central Sensitization, Wieneke said that with the exception of nerve pain, most of the issues can't be treated with medication. A lot of her information came through an eight-hour education class hosted by Mayo Clinic for people with Post COVID Syndrome.

"They more so encouraged ways to alleviate the symptoms versus medication," she said. "It's like when

Murphy experiencing new side effects

By Julie Buntjer
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WORTHINGTON — With COVID-19-related restrictions relaxing, people have tossed aside their face masks and are moving on with post-pandemic life.



Murphy

effects.

Earlier this year, The Globe shared stories of three area women dealing with a range of symptoms from exhaustion to neurological issues. Susanne Murphy was the first to be featured.

Diagnosed with COVID-19 in mid-December, she is now six months into Post COVID Syndrome and has no idea if or when she will be back to her pre-COVID health.

When an unusual early June heat wave descended upon Minnesota two weeks ago, Murphy said her symptoms really amplified.

"I didn't expect it to be this bad," she said, noting how simple tasks like walking from the car to the house sap her energy. Some days, all she can do is lay on the couch — not at all conducive to her once busy lifestyle of work and volunteer service to the community.

"I'm still having exhaustion and intermediate headaches," Murphy shared. "And the nerve pain on my right side flares up without any prompting. I can't figure out what triggers it."

The nerve pain wakes her in the middle of the night, and is bad enough to bring her to tears.

"It was nerve pain like I've never experienced before. It lasted all day," she said of recent pain in her right arm and hand. "I forced myself to do some things because the rest of my body didn't hurt."

While Murphy said she has more good moments than bad,

the bad moments are the worst. In those times, she tells herself the pain will go away eventually.

"It comes, but it always leaves. I focus on the fact that it's going to leave again," she said. "I never know how long it's going to last. When I get exhausted, I think I'm going to rest for 10 minutes and I'll be out for two to three hours. I won't hear the phone or anything unless Mocha barks."

While the exhaustion has been with Murphy since the beginning of her battle with Post COVID Syndrome, the nerve pain is more recent. Earlier last week, she experienced her first — and hopefully only — digestive issues.

As of June 1, Murphy joined an online research group in a three-month trial spearheaded by the Mayo Clinic in Rochester. Based on her symptoms and what they've gleaned from other long-haulers, they suggested she try a gluten-free diet.

"They seem to think there's a connection between gluten and the inflammatory system," Murphy shared.

No easy answers

People living with Post COVID Syndrome have a wide array of symptoms, and there's no quick pill or easy solution for any of them.

"Everything is new — there's no history," Murphy said. While she has nerve pain, digestion issues and exhaustion, others experience vision trouble or have lost their sense of taste.

Murphy has tested some essential oils, and found turmeric in capsule form to be helpful for her nerve pain.

"Listen to your body; rest," she said. "You cannot drink enough fluids. I've been drinking a lot of Pedialyte and Gatorade because I don't want to get dehydrated."

Murphy received both her first and second vaccinations to ward off another bout of COVID-19, and didn't have a

reaction to either dose. She was hopeful they would lessen some of her post-COVID symptoms, but that wasn't the case.

After six months of health-related issues, Murphy admits the exhaustion, brain fog, lack of focus and pain has chipped away at her spirit.

"I'm a person that likes to be true to my word," she said. "One of the hardest things for me is when I say I'm going to do something and then I have to cancel."

"My thought process tells me I want to do these things and my limitations won't let me," she added.

It hasn't been easy to accept help — she learned to be independent when her husband died suddenly 22 years ago — but Murphy is so thankful for understanding and supportive friends.

"Someone will come and water my flowers or offer to get my groceries," she said. "I'm blessed with a very supportive team."

After the first story was published in February about Murphy's bout with Post COVID Syndrome, she and another local long hauler, Jolene Wieneke of Adrian, created a Facebook Group for area residents living with impacts from the virus. Murphy hopes to bring the group together for an in-person gathering this summer.

"In reading about other people's struggles, it's bitter-sweet," she said. "Sometimes you'll read that they've been feeling OK for months and then, wham, something knocks them over."

"You worry that will happen," she added. "Then again, you hear of someone who's had it for nine months and is starting to feel better and see the light at the end of the tunnel."

"I know there's people out there fighting for every breath they take. I am not going to complain once about this — it's annoying. We all deal with it in our own ways."

you have an allergy, you eliminate things until you figure out what is causing you to have the inflammation. You want as little inflammation in the body as possible, because that's what's causing the issues."

Mayo's philosophy in treating COVID patients is to look at their lifestyle. Many of their suggestions address diet, she noted.

"A lot of people had success going on anti-inflammatory diets, drinking more fluids, salt suppression and exercise," Wieneke

shared. "Mayo believes that with Long COVID, your immune system is somehow attacking your body. They don't have a treatment yet, 100%, but they have a broad idea of what's going on."

Wieneke said the most difficult aspect of being a COVID long hauler is not knowing if or when she will feel completely well.

"I think it's hard for people to understand it if they haven't actually lived it," she said. "For me, the hardest part is when I have some good

days and I feel like I'm finally getting better. Then, when I start to relapse, it is so disappointing."

It has caused Wieneke to feel a lot of sadness, which resulted in her being issued an antidepressant.

"The statistics are that a lot of people have been diagnosed with some sort of mental health issue that never had it before," she said, noting that the anti-depressants have helped her.

Being able to connect with other COVID

long haulers has helped Wieneke know that she isn't alone. It's also provided a way for people to help each other if they've found a remedy for a particular symptom.

"Sometimes it's hard to know what to do because you can have so many symptoms," she said.

Wieneke hopes to connect with an occupational therapist who works with neurological issues to help her address the internal tremors, cognition and vision issues.



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