

catching DIANE ATWOOD health

Denise Kinney's muscle weakness turned out to be something serious

Catching Health podcast episode published on February 1, 2021

Diane: Denise Kinney, from Biddeford, Maine, used to be a hospice nurse, a profession she was passionate about. When she wasn't working, she'd spend hours tending to her garden and whenever she could, would climb on her Harley and go riding with her husband, Neal. And then one day in 2009, when she was only in her early forties, Denise thought she was having a stroke.

Denise: I was in the house cleaning my bathroom and I was at the sink. I looked up. I had a headache and I looked at my face and I was like, oh my goodness. My face was drooping, and I had some weakness in my leg, my left leg.

Diane: Her husband Neal saw it, too.

Neal: I noticed right away the drooping of the face, the left side and oh, my God, she must be having a stroke.

Diane: They rushed to the emergency room where they were told that Denise was not having a stroke, but doctors had no idea what was causing her symptoms. In no time, she had more.

Denise: The face got better fairly quickly, but it still shows, particularly when I get tired. My left leg almost immediately started atrophying, getting smaller around the calf and then the thigh. It was quite noticeable. And I started with severe headaches.

Diane: You are listening to the *Catching Health* podcast. I'm Diane Atwood host and producer. In this episode, you will hear the remarkable story of Denise Kenney, who after her visit to the emergency room, embarked on an odyssey to find out what was wrong with her. It would take nearly two years. Along the way she saw a variety of specialists, went through test after test and endured humiliation and frustration. Told that she should be glad that at least she didn't have such and such a diagnosis, ALS for instance, or that it was all in her head, that she was hormonal or that she was simply doctor shopping.

Denise: It was a hard few years. I'll tell you.

Diane: On a positive note, one doctor has always been there for Denise.

Neal: The first neurologist that we saw at Maine Neurology, he's been there for her since the beginning. And he is just fantastic.

Denise: He really was a godsend. He didn't give up on me trying to figure out what was wrong with me.

Diane: Eventually, a multiple sclerosis specialist suspected that Denise might have a mitochondrial disease. He gave her an article to read.

Denise: And he says, this is what I think is happening with you. I read it and I'm like, oh my goodness, those are all my symptoms. He says, I'm going to have you see this doctor and so, I went to him and he explained everything to me about mutations and genetics. And he says, I'm going to set you up for a muscle biopsy and that's how I got my diagnosis.

Diane: The biopsy showed that Denise did indeed have a mitochondrial disease. One in 5,000 people with mitochondrial disease will have inherited it from their parents. Some forms are easily identified with genetic testing but others, particularly in adults with various symptoms are more challenging. [Dr. Thomas Reynolds](#) is a pediatric neurologist at MaineHealth. He is not one of Denise's doctors, but is very familiar with mitochondrial disease.

Dr. Reynolds: There are so many different subtypes of mitochondrial disease that can show up in infants through the end of life. So, it's extremely variable and there are some very complex genetic theories as to why it's so variable. But mito is really an umbrella term for a whole host of different problems with energy function. The mitochondria, they are the cellular powerhouses, they're making ATP, the basic cellular sort of fuel. That's what you break down when your cellular processes are needing energy. This area of medicine lives in multiple subspecialties because of how complex it is, but geneticists and neurologists tend to be the people who end up evaluating and managing this most frequently.

Diane: Mitochondria exist in nearly every cell in the human body. Their job is to convert food and oxygen into life sustaining energy, and when something goes wrong and they can't do their job, cells are damaged and even die. It can happen throughout the entire body, but muscles, the brain, the heart, and the liver are especially vulnerable because they need the most energy. Each of the many types of mitochondrial disease produces a spectrum of symptoms and abnormalities that can be confusing to both patients and physicians.

Dr. Reynolds: Lots of times it's not a recognizable syndrome. The well-known, we've known about them for 50 years Leigh syndrome, MERRF, and MELAS. But you can have much more non-specific presentations where maybe you're weaker, you're fatigued more easily than the average person, maybe your brain gets a little foggy more easily than the average person. So, you have these sort of non-specific symptoms that kind of fit with mitochondrial disease, but could really be anything.

Diane: And that's why it took nearly two years for Denise to get a diagnosis. During that time, she was unable to work and was on disability, but because she didn't have a medical diagnosis, she was categorized as having a mental health issue and her benefits were capped at two years. She was about to lose them when at the 11th hour she got a definitive diagnosis. And meanwhile, her condition progressed. Her muscles continued to get weaker and by 2015, the mitochondrial disease started to affect her brain.

Denise: And It started with seizures and dystonia, migraine headaches, and then I started with some real difficulty with cognitive tasks and memory loss.

Neal: I think the first thing I noticed was she would use a similar word in a sentence. I knew what she was trying to say, she wouldn't use the actual word, it would be something similar. So, I just kind of dismissed it at first, only because, kind of like the denial thing maybe, which maybe isn't right, but you don't, I guess I had a tough time accepting it, you know, I knew it was coming, but yeah, I think that was the first thing I noticed.

Diane: When Denise was first diagnosed, her doctor prescribed a cocktail of medications meant to reduce symptoms or slow their progression, but there are no cures for mitochondrial diseases. Dr. Reynolds says there has been some promising research about the benefits of exercise.

Dr. Reynolds: You can actually make your mitochondria more functional just by exercising. Too often when we get a disabling diagnosis, we think we can't be active anymore. I have this disease and I can't be active, but we know with muscle disease, even with progressive muscle disease, staying physically active, keeping your weight in an appropriate area is so valuable for preserving that muscle function. Or you keep your muscles in better stretching shape. If you're moving towards a wheelchair, for instance, and you never get up and walk anymore you have got to do at least some of the physical therapy and exercises that keep your muscles stretched so that you don't develop contractures, for instance. You've got to keep using them, even if they're getting worse, even if you have a disease

that the doctor says is going to get worse over time. You cannot underestimate the importance of physiotherapy and exercise and continued use of those muscles to keep them more functional longer.

Diane: Unfortunately, when Denise tries to exercise, it saps her energy to the point that she can hardly move or breathe. She and Neal just bought a tricycle though, and she's going to keep trying. She also does stretches every day and says she can definitely feel the difference if she skips them for even a few days.

Part of what makes Denise's story so remarkable is that even though she's been facing mounting obstacles for more than a decade, she still has the drive to not only keep trying, but also to help other people. For instance, when she started having cognitive and memory issues and was diagnosed with dementia, she reached out to the Alzheimer's Association for support and ended up becoming an advocate for the organization.

Denise: I ended up calling the help line, talked to someone, it was so great. I called twice and it helped me a lot. It's such a great service. Peter Baker, who's no longer there, contacted me and he said, we're starting a new *Living Well with Early Onset Dementia* and I'd like you to come to our support group. And so, I started doing that and it was through that that I learned about advocacy, because I needed to do more than just showing up at a support group once a month.

Diane: She's been to the state house in Augusta several times to share her story with lawmakers and to speak in favor of various dementia-related bills.

Denise: I tell them, hey, whatever you guys need, I'm your girl, I'm going to do it.

Diane: It is that same attitude that prompted Denise to share her story with Catching Health.

Denise: I think that it's important for me to let people know that they're not alone. People who feel they might have an issue with anything that's going on with them to not give up, particularly if it's a cognitive disorder. To call

their Alzheimer's Association or if they've been diagnosed with dementia of some kind, that they're there for you. It helped me so much. And I also want people to know that my work through advocacy has been a godsend to me because I hear a lot about how brave I am and strong I am, but you know, I look at it as good medicine for me because there really isn't anything I can take or do. So, I just try to take it one day at a time and then when I do the work that I do, to me, that's like medicine for me. Because I'm doing something with what I've got to help whoever I can, putting a face to it. I'm very happy to talk to anybody.

Diane: If you would like to reach out to Denise, send an email to me, Diane Atwood — diane@dianeatwood.com. Diane has one n. I'll see that Denise gets your message. For more information about the Alzheimer's Association or to find a chapter near you, [visit alz.org](http://visit.alz.org), and to learn more about mitochondrial disease, a place to start is the United Mitochondrial Disease Foundation at umdf.org. You have been listening to the *Catching Health* podcast, which is sponsored by Avita of Stroudwater, a memory care facility and Stroudwater Lodge, an assisted living community, both in Westbrook, Maine. For more information about them, visit Northbridgecos.com. To read my blog *Catching Health with Diane Atwood*, listen to more episodes of the *Catching Health* podcast, or see a transcript of this podcast episode, go to catchinghealth.com.

Finally, many thanks to Denise and Neal Kinney for sharing their story and to Dr. Reynolds for his expertise.