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### Medicare Resource

#### Know Your Medicare Rights

By Cate Kortzeborn  
(Reprinted with permission from IG Living)

As a person with Medicare, you have important rights. One of them

September 2016

In honor of September Pain Awareness Month, the NAF invites you to share your personal stories, experiences, questions, news and tips, with our readers and the neuropathy community. Your story may be published in an upcoming Patient Voice newsletter! Simply email us at [info@neuropathyaction.org](mailto:info@neuropathyaction.org).

### Patient Story

#### MMN Patient Story

By Sarah Laurianti

My disease first started as a funny little bar trick in 2006 - my twitchy thumb. We'd laugh as the abductor pollicis brevis would flutter and shake, my right thumb shaking faster than I could recreate intentionally. As the months wore on the twitching got worse and soon my right thumb began to cramp up on me. The cramping was so severe that I would physically need to

is the right to appeal.

An appeal is the action you can take if you disagree with a coverage or payment decision by Medicare or your Medicare health plan. For example, you can appeal if Medicare or your plan denies:

\* A request for a healthcare service, supply, item or prescription drug that you think you should get.

\* A request for payment of a healthcare service, supply, item or prescription drug you already got.

\* A request to reduce the amount you must pay for a healthcare service, supply, item or prescription drug.

You can also appeal if Medicare or your Medicare Advantage plan stops providing or paying for all or part of a healthcare service, supply, item or prescription drug you think you still need.

If you decide to file an appeal, you can ask your doctor, supplier or other healthcare provider for any information that may help your case. Keep a copy of everything you send to Medicare or your health plan as part of your appeal!

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## Stroke Information

### Recognizing Stroke

By Cate Kortzeborn

(Reprinted with permission from IG Living)

Stroke Information & Resource Guide  
A stroke is a serious and sometimes life-threatening condition. It is a leading cause of disability and the fourth leading cause of death among Americans. Until recently, if you were to experience a stroke, supportive care was all that was available. But now, stroke management has progressed to a point where a stroke can be stopped in its path.

There are treatments available that can prevent or limit disability caused by a stroke as well as saving many lives. The success of such treatments is dependent upon how much time has passed

use my other hand to straighten my thumb back out. Certain that it was from all the typing at work I went to the doctor and filed a work comp claim.

The first doctor I saw told me I had tendonitis and prescribed a wrist brace and physical therapy. It was good in theory but in reality it only kept me from being able to manually straighten out my right thumb when it cramped up in side the brace. I must have been the most frustrating patient for my therapist, Paula. Some days she would ask me to pull this cord, squeeze this ball, push this block and I would pass with flying colors. Other days it wouldn't matter what she tried, my hand would not cooperate.

One day I sat at my desk at work when "the moment" happened. It was the moment when I knew that this was no longer a funny joke, an odd coincidence, but a real problem. I looked at that right thumb and it refused to bend. *Bend, little thumb. Just bend* I willed it, but the connection between my brain and thumb had been lost. It was almost like the call had been dropped between the two. Panicked, I called my supervisor who sent me back to the doctor.

I remember "diagnosis day" so clearly. The doctor had done the EMG on one arm and one leg. I'd gotten myself put back together and he had asked me to wait in the room. He came in with a resident who must have been there to learn how to deliver bad news. Her eyes and nose were red, tears trickled down her face, and she had a look of gut-wrenching sadness and pity. The doctor sat down, looked squarely at me, and asked if there was someone we could call. *Call? Why call someone?* The next doctor specialized in carpal tunnel and other such disorders. His disinterest in my condition was disheartening. He said it wasn't anything he could fix and recommended I see a neurologist. That's then things got very scary very quickly. The neurologist did the same battery of tests that we're all given. Stimulus. Reflex. EMG. To this day I tell people if anyone asks if you want an EMG the answer is no - those are the worst!

Distracted by the resident, the conversation began to swirl quickly out of my grasp. The doctor looked down, breaking his gaze, and told me with 90% certainty that I had ALS. The resident broke into full sobbing tears as I sat there alone. Lost. Confused. Did you have questions? *No.* Do you know what this means? *No.* He mentioned a second opinion and a referral to the Mayo Clinic in Rochester. His parting words: "just don't Google it." After three long days of following the doctors orders I broke my Google vow. I sat at work trying to spell "amyotrophic lateral sclerosis." The information I found seemed innocuous at first. ... generally affects people in their 40s to 60s but can present earlier ... causes a weakening of muscles ... once it presents death is likely within four years. Four years? Four years! I was 25! I had more in me than just four years! I broke down that day at my desk, sobbing uncontrollably until a co-worker called my best friend Scott to come and get me.

Those early days are so crystal clear to me. I remember Scott coming to pick me up and walking me to a bar up the street. We sat in the basement of "our bar" and drank beer and cried and toasted to the 10% chance that the doctor was wrong. Six weeks passed until I was able to get in at the Mayo Clinic.

since the stroke symptoms appeared. Therefore, the early recognition of a stroke by the patient or their family is of the utmost importance. This article will attempt to give you the information you need to recognize a stroke and respond accordingly.

### **What is a Stroke?**

The brain has blood vessels that are dedicated to providing each and every region with the oxygen and nutrients that it needs to survive and function. Over the years, plaque from cholesterol and other lipid substances starts to build up in the blood vessels and causes them to narrow. If that plaque ruptures and causes damage to the vessel wall, the body tries to heal it. Clot forming molecules will reach the site and clot off the vessel. Once the blood vessel is closed, there is no blood flow to the tissue beyond the blockage. Sometimes, the clot will dislodge, travel in the blood and block a smaller vessel downstream. Without oxygen and nutrition, the tissue beyond the blockage will begin to die.

The symptoms and size of a stroke will depend upon the location of the blood clot. Stroke due to such an underlying mechanism is referred to as ischemic. This is the predominant form of stroke. At least 8 out of every 10 cases of stroke are ischemic strokes.

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## **Educational Online Videos**

### **Educational Videos Seen By Over 7 Thousand People in August**

The NAF is committed to reaching patients with education, aiming to ensure the ability to obtain the resources and information necessary to access individualized treatment to improve quality of life.

The NAF continues to partner with Chicago based Context Media Health (CMH), a

Six weeks of thinking my death was imminent; of making plans to enjoy every moment; of preparing to die. I'd been scheduled to spend three straight days with the doctors at the Mayo Clinic, however after only the first day a gentle doctor with a caring smile held my hands and gave me the wonderful/awful news - I have multifocal motor neuropathy with conduction block. I would live!

As anyone with MMN knows living with it isn't always easy. A medication reaction left me hospitalized with blood clots in my leg and lungs for a week. My veins were so thin and weak from being regularly punctured that my IV injection sites had moved from my hands to my arms to my feet. I missed work - a lot of work in the beginning. When I moved and changed jobs I had to jump through hoops to get my IVIG covered. I had to explain to insurance companies that my medicine was "medically necessary" and not experimental. After having a port put in to make infusions easier I was hospitalized again with PE. The road was rough, but I pressed on. Most people now don't realize there's anything different about me because I try damn hard to keep it from defining who I am. In fact since being diagnosed I've purchased three houses, lived in three states, gotten married, and had two natural babies that I have breastfed for 14 months and 20 months (and counting).

A note on my pregnancies: pregnancy weakens the body and in an already weakened body like mine I found that my symptoms, especially weakness and cramping, were exacerbated with both pregnancies. I became weaker and weaker as my belly got bigger and bigger. Once my babies were born, though, my symptoms leveled out. Thankfully I was able to regain some strength after each one!

Ten years later I still get my infusion every three weeks. Luckily for me I can be infused at home on the weekends so I don't miss work anymore. My left hand has become weak and atrophied, but I still work full time with the aid of an ergonomic keyboard and Oval-8 braces when my fingers won't straighten out far enough. My right leg has begun to atrophy as well, but I've found that roller derby (Yes! Roller derby!) has become an excellent form of physical therapy for me. The repetitive weight bearing motions for my legs combined with the incredible support and pressure of my team (who don't know about my uniqueness) makes me both physically and emotionally stronger every day. I've never succumbed to my disorder. I'm not an MMN patient and I don't "suffer" from it. I just happened to be a wife, mom, crafter, DIYer, Roller Girl with a quirky little neuropathy. Stay strong!



Sarah Laurianti

## **Chronic Pain Resource**

mission-driven organization, committed to patient education. Through CMH's broad reach in provider waiting rooms and hospitals, the partnership provided over 7 thousand impressions/possible views of NAF educational videos during August 2016.

CMH is currently helping the NAF reach more patients by showing our Multifocal Motor Neuropathy (MMN) and Diabetic Peripheral Neuropathy (DPN) Public Service Announcements throughout the U.S.

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## Drug-Free Remedies for Chronic Pain

By Loolwa Khazzoom, AARP The Magazine

In the early 1980s Cynthia Toussaint was a promising young dancer, close to snagging a role in the hit TV series Fame. But then she tore a hamstring in ballet class. Usually such tears heal on their own, but in Toussaint's case the injury led to the development of complex regional pain syndrome—a little-understood disease characterized by chronic pain that spreads throughout the body and can be so excruciating that even the touch of clothing hurts.

"It felt like I had been doused with gasoline and lit on fire," recalls Toussaint, now 48, who was a student at the University of California, Irvine. "I can't imagine surviving something more devastating."

Toussaint had become one of the many Americans suffering from chronic pain—as many as 76 million, according to the American Pain Foundation—who are dealing with everything from arthritis to cancer. And like many pain patients, she struggled to convince doctors her symptoms were real. Toussaint says she was refused X-rays, misdiagnosed, and dismissed as crazy. "One doctor patted me on the head, saying, 'You're making a mountain out of a molehill, darling. You need to see a psychologist,'" she recalls. Meanwhile her disease—often reversible if treated early—only got worse.

Bedridden and folded up in a fetal position, she was unable to brush her hair, shower, or use the bathroom unaided. She teetered on the verge of suicide. Finally, after 15 years, a switch in medical plans introduced her to doctors who believed her. But by that point, the pain medications they prescribed could not reverse her condition. Worse, the drugs left her with a slew of side effects.

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Neuropathy Action Foundation

[info@neuropathyaction.org](mailto:info@neuropathyaction.org) | [\(877\) 512-7262](tel:8775127262)  
1950 Old Tustin Avenue | Santa Ana, CA 92705

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Neuropathy Action Foundation, 1950 Old Tustin Avenue, Santa Ana, CA 92705

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