

Missed-Diagnosis: My 4 Early Signs of MS



Before we begin, my intent is not to diagnosis anyone with MS. I can't do that - only a healthcare provider can. Rather, my intent is to educate. My message is simple: don't ignore signs and don't allow anyone to ignore you.

Here we go...

I am a "doctor regular." Meaning: I. Go. To. The. Doctor. I keep up with my appointments, get check-ups, and when something is wrong, I investigate.

But I still managed to end up misdiagnosed and ignored. I trusted the professionals and allowed myself to be misled, and quite frankly, mistreated.

Getting practical, successful medical care as an obese Black woman is **difficult**. Being typecast, dismissed and undervalued as a patient is not a good feeling. But even worse is not knowing that it's happening. I'm a smart woman, but even with my level of intelligence, I was ignorant to the signs that something was going terribly wrong inside my body. Here's what was missed:

- **Painful vision loss in one eye**

The summer before my 34th birthday, I started having migraines and blurred vision. An annual eye exam later that summer revealed that I had a mass on my optic nerve and was told I needed to see a neurologist right away. I had to wait 4 months to get in with

the neuro. Appointment comes, and I was told my weight was causing my spine to work in overdrive and produce too much fluid causing a blockage on my optic nerve. The answer was to lose weight and have a spinal tap. Both happened, and pain was relieved, perceivably because of the procedure. However, the truth is I was suffering from optic neuritis, a common MS symptom, and by the time I had the spinal tap (a year later), the lesions on my brain were not active. Missed opportunity because I didn't get to the doctor soon enough.

- **Persistent weak and numb limbs**

Throughout my mid- to late- 30s, I had many times when my legs gave out on me. At work, home, everywhere. I completed a mud run one time and held up the entire race because I couldn't get my leg over the wall. Went jet skiing, had to be emergency lifted out the water because I couldn't get my leg into the boat. Went to the doctor, took a nerve test... nothing. Told to lose weight. I've been able to track my history of complaining about leg numbness. Imagine a patient reporting 1 symptom for 10 years and no one pressing through to figure out why. I let them get away with this.

- **Severe, ongoing dizziness**

Dizziness is not normal. I repeat: Dizziness is not normal. Dizziness that causes you to fall or lose balance... yeah, get that checked out. I did. Ignored and sent home. Too fat. Blah, blah, blah....

- **Facial paralysis**

This is one of the final symptoms I experienced before MS fully announced itself in my body. I experience facial palsy for 72 hours before getting medical assistance. At the ER, I had to convince the medical team of what I was experiencing. I refused to leave without getting help. And the rest is MS history.

Here's the truth.

[Black people have a higher risk of getting an MS diagnosis than white people.](#)

There is a medical belief that Black people are less susceptible to MS. However, recent research indicates a higher incidence of MS in Black people. Black people with MS may also have more aggressive disease progression, greater disability and different symptoms, including more walking, balance, and coordination problems, more cognitive and visual symptoms, more frequent relapses with poorer recovery, and earlier disability onset.

Ironically, I didn't fit the MS profile. I didn't get the objective and humane medical treatment I

deserved. Despite the challenges leading to diagnosis, this experience has taught me the importance of self-advocacy. I've learned that I am a vital member of my medical team and that it is important to ask questions, do the research and actively participate in my treatment plan. I'm also learning to elevate my thinking from "getting treated" to being in control of receiving that treatment that is appropriate for me. Even though I live with MS, I am powerful beyond measure and knowing how to advocate for myself is empowering.

Editor's Note: Learn more about getting an MS diagnosis on the [Society website](#).

The National Multiple Sclerosis Society is proud to be a source of information on multiple sclerosis related topics. Unless otherwise indicated, the information provided is based on professional advice, published experience, and expert opinion. However, the information does not constitute medical or legal advice. For specific medical advice, consult a qualified physician. For specific legal advice, consult a qualified attorney.