

MS as a cure for mediocrity



My disease has inspired me to develop a new outlook on life.

by Amy Black

Everything I knew about multiple sclerosis came from “The West Wing,” a television drama about a fictional White House administration under President Jed Bartlet, played by actor Martin Sheen. When the show reveals that Bartlet has been diagnosed with MS, I remember thinking, “Poor fictional character. That must suck.” I gathered that the disease was great for ratings, but I personally couldn’t answer fundamental questions about MS. Was it even real? Contagious? Fatal?

Occasionally, this very real condition returns to the news, as it does when someone famous, such as Jack Osbourne or Selma Blair, reveals their diagnosis. Through today’s instant media, we can learn about those misfortunes seconds after disclosure, digest their personal accounts and read the attached comments from well-wishers and trolls alike.

In 2006, I squirmed before a neurologist who was not particularly gifted at dispensing bad news. I, like nearly 1 million in the U.S., now owned a fictional character’s disease.

In my low-budget, low-tech, pre-smartphone days, I did what any responsible adult would: I headed straight to the bookstore. The extent of the MS literature available consisted of a scientific textbook and a rather uncheerful autobiography of talk show host Montel Williams. I bought both.

I called the National Multiple Sclerosis Society and asked for every booklet, pamphlet and

brochure they had. Because I'm a drill sergeant's daughter (I make a list to organize my lists), I bought a file box and organized these printed resources alphabetically by topic.

In some ways, I envy those discovering their diagnosis in this news-in-our-palms tech age. We have an astonishing array of immediately available sources to educate ourselves about mystery conditions. We can scour WebMD, Google every symptom and read first-person accounts no matter where we are. Few are running to a bookstore to learn more about anything anymore. However, perhaps the drawback is too much unfiltered information, which does not necessarily protect us from misunderstandings, self-diagnosis and unsafe fads.



Amy Black with her support dog named Zhavier Orion. Photo courtesy of Amy Black

In truth, my diagnosis didn't hit me quite the way Selma Blair experienced. Unlike Blair, I was neither relieved to have an answer nor overcome with grief over perceived outcomes. There was no one telling me the right or wrong way to handle MS, so I simply opted not to dwell. I didn't panic, shut down or cry. I read the brochures, filed them away and moved on. MS didn't require much personal attention for a few years, until the foot drop started.

Eventually, my balance made strangers question my sobriety and my bladder turned geriatric. Outings began to require reconnaissance — how far from the parking lot, how many stairs, where are the bathrooms?

The idea that my teetering version of walking might degrade further made me reconsider my lack of a proper mission statement. Let's face it: there's nothing like an incurable disease to make you recognize a mediocre life being endured. I'd spent my 20s focused on uninspired employment and lacked significant hobbies. I did nothing exemplary. I had no backlog of exciting memories. I wasn't just vanilla...

I was unflavored!

My reckoning? I ought to make use of this set of limbs while I can. My personality suits MS, a disease that prefers I follow its sometimes-isolating ideations — going nowhere, doing nothing, embodying the word “no.” Inhabiting a “while I can” lifestyle means adding “yes” to my vocabulary.

Through an accidental yes, I discovered my passion: urbex photography. Urban exploration involves using my shaky, unresponsive legs to traipse and trip through abandoned properties, creeping between rotted timbers and crawling across unstable floors to document the splendor of ancient homes, asylums and factories. This has become, for me, the definition of “alive,” of “yes.” And a subtle middle finger to MS, despite the host of challenges it brings to the hobby.

With 12 years behind me, I can actually say that MS is responsible for the best pieces of my current existence. Because of my limitations, I’ve adopted a new outlook, a new determination.

An incurable disease is a stellar excuse to craft a mission statement and then live it out.

Amy Black lives in Morrisville, Pennsylvania, where her two dogs and three cats run roughshod over any hope for order.

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Amy Black’s urbex photography can be found at [instagram.com/zaedah.urbex](https://www.instagram.com/zaedah.urbex). See her portraits at [instagram.com/zaedah.black](https://www.instagram.com/zaedah.black).