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Language of the Ill: Observations on Disability in a Time of Pandemic

Deonte Osayande

I am no longer as passionate about performing poetry as I am about writing it. I realize that, as I sit in my house, having not performed a poem in months. It brings me anxiety, and although my concern is relieved moments later, the world of poetry slam has now become too much for me, where it was once everything. I do not even remember any of my poems. And, strangely, I am not entirely sad about this new development.

I never considered myself part of the land of the healthy. Even before COVID-19 I knew I had narcolepsy and depression. These were accepted facts that I recognized within myself. I thought I knew the language of the ill, how we are struck down when we least expect it, how illness speaks in a particular fashion. I had long felt the effects of being chronically sick before the global pandemic. I knew how health, private and public, could (and does) change instantly. Like realizations about poetry preferences, things that are permanent never really are.

I sit in an empty classroom at the end of the semester, a semester cut short by social distancing. I find myself facing one of my greatest fears. It is not some sort of apparition, or creepy ghoul, but it is a simple reality for many of us. It is the specter of MS, otherwise known as multiple sclerosis. It first appeared in October of this past year, after a normal weekend. I was running to work, but then, oddly enough, my balance appeared off. I used to run track, so it was a strange sensation to have steps

become more and more wobbly as I moved forward. At first, I thought it was vertigo, so I went to work, taught my classes, and waited for it to go away. The thing is, it never did.

In the coming weeks I would be fitted for glasses and given a prescription for dizziness. I was never dizzy and I had not worn a pair of glasses since I was a child. Now, it seemed that I was severely nearsighted. Then I started noticing my forgetfulness and how the poems I wrote for my live performances were all lost in the thick layers of brain fog. I could not recall more than the first few lines of any poem, and that is when I knew something was wrong. I consulted the one person I know who had fought MS and won—my mom (biologically my grandmother).

I confessed to her about my struggles, and she was one of the first people to suggest it might be MS. My father also suffers from the disease, and it has completely debilitated his life. Once a funny, outgoing man, he now stays in the confines of his room, often just to his bed, an almost complete exercise of social distancing. He occasionally comes out in his wheelchair, like he did to meet my wife, but his speech is barely above a whisper. His words are hardly audible. I remember he was saying something to us at the time, but I could not make it out. I just tried to guess what he wanted, and most of the time, through piecing together this dialect of the ill, I was able to. For the instances where I was unable, where fluency stopped, I had to ask his wife or my younger siblings to translate what his illness had turned his language into. Now more than ever I could see that he spoke the language of the ill.

As the years have gone by he has become thinner and thinner and thinner to the point that I am afraid every time his wife calls that the news will be he has passed away.

Multiple Sclerosis is an ailment that progressively eats away at the nerve cells in your brain and spinal cord.

Think about that.

It starts in the place that controls thought and action. *The center of our being.* Then it radiates outward, hitting all of the other parts of ourselves as it goes. It can cause numbness, impaired speech, blurred vision, and severe fatigue. And those are just the physical impairments. Eventually it starts to affect our social being too: how we work, how we play, how we relate to the world in our bodies.

I have known these things since I was a child, watching family members fight. As intimately as I knew it, though, I never thought I would have to face it. But that is often the way with disease—always a risk, but typically something happening over there, to others, separated from ourselves by oceans and bodies and lived experiences. Yet that assumption is no vaccine, and when I saw a neurologist after symptoms persisted, he confirmed that it was one of two things— either MS (that skeleton stumbling in my closet) or just a pinched nerve (oh, to hope). I wanted, of course, for it to be a pinched nerve. But what I feared was that my genetics were finally catching up with me. Like a rival in a track meet, or a competing poet in a slam, slowly gaining, gaining while I was fumbling more and more.

I tried to run from it for so long, but maybe that was my problem. I spent so much of my life running from my genetics. I was so busy blazing my own trail that I neglected the roles that the past plays within all of us. My biological father played football in college, and I did not consider that in my athletic background; rather, I ran track and field, focused on the type of athlete I wanted to be. My mother (grandmother) was an English teacher, but I did not think about how that fed into my background as a writer or as an English professor. We all come from somewhere, and maybe it is important to acknowledge where that is to see where we are headed.

I was initially tested several times, and everything came back negative. I had an MRI on a Thursday. The neurologist called me that Friday and confirmed that the shadow following my whole life had finally caught me.

I have MS. No denying it.

There is inflammation on my brain and spine, and they just needed to determine what kind and the severity of my condition. I am not afraid, not like I was before. I knew fairly quickly what it was, and the neurologist complimented me on coming in because it might be early enough to be treated. In any case, it will be difficult. At least in knowing what you are up against you can take progressive action to fight it. I am not going to quit, as I have not with any of my other health issues,

I'm just at the starting line.

Feet in the blocks.

The gun is about to go off.

But then we shift gears.

Let's begin with the date and the time, the pandemic filling our screens and flying through the air on conversation started in Wuhan, China, around November of last year. Scientists are calling it the "novel" coronavirus. The epidemic has spread globally to the point that every nation is dealing with numerous fatal cases of it. The United States has barred travel from all of Europe, and conversely Canada, (the nation bordering my city) has made travel to and from the United States illegal. Flights are really cheap nationwide, but we are all advised to quarantine ourselves in our own homes until further notice. Although many people are disobeying that order, I am not.

This is an epidemic on a scale that modern society has not seen for quite some time. And I am not just talking about the spread of an infectious disease. A few days after the New Year started the president of the United States launched an airstrike on an Iranian diplomat and killed him. There are even conspiracy theories that the United States engineered this virus as a weapon to be unleashed

on rival nations. This idea comes after Trump has suggested that China is responsible for engineering the virus.

It is just a war of words. The words are there just to distract us from the fact we are living in an uncertain present, with an uncertain future, with leaders who cannot agree on what has happened in the past. The war of words is meant to distract us from the fact that a virus unleashed is not in the realm of science fiction but a reality in a world where diplomats are killed, where racist reality television stars reign as temporary kings, where reality succumbs to the viral sting of Twitter.

This all leaves us in quarantined isolation in a country with a leader that I, and most Americans, did not vote for, combatting a disease no one expected. Speaking, in a way, the language of the ill.

To say it is an uncertain time is an understatement. Yet as I sit at home, writing, always writing, and come to terms with how my career as a poet will change now that we live in a world of social distancing, and I personally deal with MS, I see that these new developments can be mourned, can be feared, but ultimately must be absorbed into the lexicon of our work as writers. We are starting another journey with the same voices we had prior, but with a new language. We can only hope that it carries us as far as we previously wanted to go.

Deonte Osayande is a poet and nonfiction writer from Detroit, Michigan. He is the author of three collections of poetry.