



5 Things You Should Know About Dysautonomia

1. **Dysautonomia is a group of neurological disorders** that impacts over 70 million people around the world. It is an umbrella term used to describe neurological disorders that cause malfunction of the Autonomic Nervous System (ANS), which regulates heart rate, blood pressure, digestion, kidney function, temperature control and more. Dysautonomia occurs when the sympathetic nervous system (fight or flight) and/or the parasympathetic nervous system (rest and digest) are not working properly.
2. **POTS (Postural Orthostatic Tachycardia Syndrome)** is a form of Dysautonomia that I myself struggle with. Sadly, 75% of people diagnosed with POTS are *misdiagnosed* for an average of 4 years and 2 months prior to being diagnosed with POTS and see an average of 7 different doctors prior to diagnosis. The most common age of onset is 14, and about 90% of POTS patients are female. This impacts an estimated 1,000,000 to 3,000,000 Americans and millions more around the world, and is actually more common than well-known medical conditions like MS. The Mayo Clinic found that the disability seen in POTS is similar to the disability seen in Congestive Heart Failure or COPD. 50% of POTS patients have to travel over 100 miles to receive care; I myself have to travel to Birmingham, AL.
3. **Dysautonomia is considered an invisible illness**, which means that on the *outside* we look completely normal but on the *inside* that is not the case. I suffer from Neurocardiogenic syncope which is a form of Dysautonomia that no one would expect me to have because on the outside I look fine, but “episodes” can include a rapid drop in heart rate, then blood pressure, abrupt loss of motor function (legs giving out), non-epileptic seizures or convulsions (so not fun), fainting and falling.
4. **Dysautonomia can impact the entire body:**
 - a. Cognitive Impairments what we call “brain fog”
 - b. Tachycardia (heart rate too fast)
 - c. Bradycardia (heart rate too slow)
 - d. Nausea and Severe Gastrointestinal Distress
 - e. Blood pooling in the extremities
 - f. Low or High Blood Pressure
 - g. Lightheadedness and Fainting
 - h. Chest Pain and more
5. As a Dysautonomia patient, for me the **hardest part was how long it took to be diagnosed and the consistent feeling of not being taken seriously**. After 7 years when I *finally* received a diagnosis, it was bittersweet. I had finally received validation and confirmation that I wasn’t crazy, and that symptoms like fainting, constant nausea and rapid heart rate for no reason were NOT normal; but at the same time, learning there was no cure? That was hard. Once diagnosed, I had to find a specialist to care for me. Physicians who treat Dysautonomia patients are difficult to find, so I was fortunate to find a wonderful specialist in Birmingham, AL.

Basically, all one can do as a Dysautonomia patient is take each day as it comes. Some days I feel ok, and others I feel like I’ve been hit by a truck. And then, there are those days I can barely get out of bed in the morning! Most people don't know that there is anything wrong with me because with an "invisible illness" you look fine; so when I’m having an episode that includes outwardly visible symptoms like convulsions -- people typically think I'm having a seizure, and it kinda freaks them out. There are also times when I have to sit down because my blood pressure has dropped, and I know I’m about to pass out. Some people who do not know about my illness (or understand it) may treat me like I’m lazy or dramatic -- all because I look fine on the outside. So, dealing with that can be tough! But again, all I can do is take it day by day, and take rest in the fact that things could be so much worse. There is always going to be someone out there who has it harder than I do.

So on the days that I can get up in the morning without having to will myself to stand, I am so grateful that God has given me another day to live my life to the fullest with family and people I love. My faith *definitely* helps on the days when giving up seems like the only option.

Happy National Dysautonomia Awareness Month: Make Some Noise for Turquoise!

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