A Literary Milestone On the Road to Understanding Invisible Illness

Book Review by Emily Weiss

“The Dysautonomia Project” is a fantastic read, earning 4 out of 5 Emily stars. It is a cover to cover prize, with poignant emotional stories from patients, and neuroscience that the general public can process. The neurologists who worked together to write this did not skimp on the science, nor did they undermine the power of our Autonomic Nervous System. They validate the struggle of a malfunctioning ANS, and the list of bodily functions that *one* neurological system regulates. Blood flow, digestion, alertness, temperature regulation, the list goes on. I think it can be hard for people to grasp what having Dysautonomia is like, because most of us take our unconscious functions for granted. Accessible language throughout the book is also a HUGE asset, when it comes to being understood.

“The Dysautonomia Project” isn’t just a textbook of cold medical facts. The book is woven with confessions from real patients, which made everything feel so much more human. Neurological illness is a topic that doctors and everyday people struggle to grasp, especially one that is invisible, underdiagnosed, and primarily affects young women. I am a 23 year old woman with this condition, and I want to make a difference in the lives of people with this condition. I have been trying to raise awareness for my community since I was 13 years old, and I wanted to read this book to better understand the disorder. More than anything, I wanted to know how it might look in people besides myself. I am just one person, and Autonomic Dysfunction is a diverse umbrella term.

You may ask yourself, “Why is this book missing a star, despite being so great?” Truth be told, I expected more coverage about endocrinological issues in Dysautonomia patients! There was so much depth on the neurocirculatory features of this illness, and it was explained wonderfully. I would’ve loved to have read more about all of the endocrine issues that correspond. Irregular adrenal responses were covered, as well as the effect they have on the ANS. The book mentioned that some patients have fluctuations in blood sugar. For this reason, the doctors did stress the importance of a low-carb, high protein diet. Hormonal imbalances were also touched on. Still, they never actually named Polycystic Ovarian Syndrome, Adrenergic Postprandial Syndrome, or Reactive Hypoglycemia. The symptoms that occur when hormonal, glucose, and adrenal imbalances happen, can be so extreme and painful. They can also be a key to recovery or remission. They play a big factor on some of the biggest symptoms: fainting, brain fog, fatigue, shakiness, and feeling painfully “on edge.” I feel that the book mostly focused on circulatory issues, and how to combat them.

The book really opened my eyes to the power of neurotransmitters, especially ones that help people pay attention and stay energized. I always thought cognition symptoms were more so related to blood flow, and not neuro-chemical factors.

 “Most patients with POTS have pronounced cognitive difficulties, such as inattention, which appear to be more pronounced in periods of anxiety or depression. Neurotransmitters such as norepinephrine, dopamine, adrenaline, serotonin, and acetylcholine, which help the nervous system work, are often released abnormally.” (page 165).

The authors validate the intense brain fog which so many POTS patients must learn to navigate, as well as warn the risks of using psychotropic drugs.

“It is important to use caution, especially initially, when taking antidepressant medicines such as SSRIs or SNRIs, or other medications such as ….**(CONTINUE QUOTE LATER)**”

 This is really an important aspect to include in a book which many POTS patients and family members will read, because while anxiety and depression can happen in chronic illness sufferers, medicines can exacerbate autonomic dysfunction. It was nice to see this in writing. I have struggled to explain this to family members, who see me struggle with anxiety due to my condition, but approach medication with caution. I hope neurologists and neuroscientists will get a better grasp on how to dose psychotropic drugs when treating patients with Dysautonomia.

I want to revisit the symptom that is “brain fog,” which is one of the most strippling “invisible” symptoms of POTS. It is strongly connected to the body’s hemodynamic response, and causes lightheadedness, “foggy” thinking, and mental fatigue. Even when patients are not experiencing more severe symptoms of POTS, brain fog is common. It fluctuates depending on several factors. Oscillatory Cerebral Blood Flow is a common problem which disrupts the hemodynamic response, and how much blood is circulating around the brain.

Doctors can trigger brain fog and other symptoms such as lightheadedness by conducting a Tilt Table Test, and seeing how the body responds. Patients report symptoms at different positions, and changes in circulatory status can be observed through medical equipment. POTS patients suffer from Orthostatic Intolerance, aka, pronounced symptoms when upright. When blood is not properly flowing around the body, the heart works extra hard to overcompensate. Sometimes it pools in the legs and arms, and can cause visible discoloration. This can feel as if the body is running a marathon when a patient is doing just basic tasks, which include bending over to do laundry, walking around the store, or taking a shower. This is why Tachycardia is such a big struggle in this community, and why the disorder is confusing to treat. While a stimulant may help cognitive symptoms and fatigue, many patients have accelerated heart rates, and this is a risk.