

Treating MS in a Universal Healthcare System



I often get asked how our healthcare in the U.K. is different, and what that means for MS appointments and medications. In the U.K., as you may know, we have the National Health Service (NHS). To us, our NHS is the national treasure that provides us with free healthcare. While it is great, it does have its downsides.

My diagnosis story was admittedly uncommon. For a lot of people, it's at least a year of strange unexplained symptoms. For me, it all happened in three days.

Our Accident and Emergency department (A+E) was where my General Practitioner doctor (GP) told me to go and get checked out for a stroke. I was 22 years old and only ever visited hospital to visit my grandma. Needless to say, I was terrified.

There's usually an expected wait time in our A+E departments of 4+ hours, and they are busy and chaotic. I ended up having to be admitted into the stroke ward surrounded by lots of 70-year-old ladies, shouting and screaming. We have a mix of wards in our hospitals, which are either male or female-specific (you get a choice which you prefer to be on if you are transgender or transitioning).

The standard of care, from what I experienced, was generally very high, and I felt very looked after by the nurses on the ward. Everything generally does move a lot slower than if you were a private patient. A private patient is one who pays for their healthcare, often receiving things like their own room, reduced wait times and specialist treatments.

The best part about staying in the hospital was the drinks trolley. As you probably know, in England, we love a cup of tea. Every few hours in a UK hospital, a trolley will come round with tea and coffee, and a selection of cakes and biscuits. That was the absolute highlight of my stay and made everything feel so much more comfortable. Do they have something like that in the U.S.?

I was taken down to various departments via a wheelchair for MRI scans and CT scans, even though I could walk. It made me feel weirdly special. Two of the MRI scans were in the hospital's parking lot, which is apparently not uncommon as our hospitals are a lot smaller.

They discharged me on the third day, after telling me to go home and Google MS for myself. I didn't get any leaflets or any sites where I could find information and I nearly left with the cannula still in my arm because they'd forgotten to take it out.

Every 6 months or so, I now have appointments with either a neurologist or an MS nurse. My MS nurse is amazing, and I even managed to convince her to come on my podcast and ask all the burning questions from our ENabled Warriors Facebook group. The neurologist I see is never the same one and having to explain absolutely everything to a new person every time is exhausting. It's one of the reasons I created the ENabled Warrior symptom tracker so that I could make sure to have accurate information to give to each neurologist.

Treatment wise, I didn't get a choice on treatment. I remember the neurologist holding up his hand and saying "imagine each of my fingers represents a different medication, the height of each finger represents the effectiveness of the medication. I want you to go on this one," pointing to a mid-height finger.

And that was that. I didn't know any better, I thought he was in a better position to decide treatment for me as he knew what he was talking about, so I agreed. It was the worst mistake I ever made. He chose an injection treatment three times per week that is supposed to go into the fatty layer under your skin. Thing was, I had no fat on me. It caused so much pain and depression for the best part of a year and a half.

"A new treatment is coming, don't worry!" My MS nurse kept telling me on my almost daily call. I couldn't take it anymore.

Eventually, they put me onto Tecfidera, and other than a few stomach issues at the start, we've been good together for 5 years now.

How different was your diagnosis story with U.S. healthcare?