It Could Be Worse

October 12, 2015 By Nicole Lemelle

“Never give up. Today is hard, tomorrow will be worse, but the day after tomorrow will be sunshine.” ~ Jack Ma

A few days ago, I looked at my calendar and saw it was time to receive another dose of my MS medication. Since being diagnosed with SPMS, I’ve been taking Rituxan (rituximab). I chose this drug because currently there is no treatment for secondary progressive multiple sclerosis. Also, I have tried various MS medications and they all failed. So I decided to give Rituxan a go.

Rituxan is more commonly used to treat Non-Hodgkins lymphoma, but it also has been used successfully to treat MS. There was a Phase 2 study in people with relapsing forms of MS, which had favorable results, but no Phase 3 study was taken.

The good part is, I only receive one dose of the drug every six months. Conversely, it is an all day process. It takes a long time because I also receive doses of saline and solu-medrol (steroids). The medicine is administered through an IV infusion at my local hospital. For anyone considering taking this drug, I advice you to bring something to keep yourself busy because the process can last up to 8 hours. This particular day, we sat in the infusion center from 8am to 4pm. The center I attend provides private treatment bays with flat-screen TVs and music systems. Also to helps pass the time, I usually bring my phone, a book and earphones. And since I’m there so long, I ask to sit near a window or under a skylight so I don’t feel like I’m in a cave.

Once they start the IV, it fills me with a large amount of fluid. This usually makes me feel very cold so I try to dress appropriately. Also, the fluids cause me to use the restroom a lot. I have a catheter in place and we have to empty it at least two times while I’m there.

After about 4 hours in the center, my nurse takes my order for lunch. They also provide lunch for my husband who usually sits right next to me the whole time. On this visit we got a sandwich, chips, some fruit and a drink.

I have had four Rituxan infusions, so it is becoming routine for me. Surprisingly, the whole process has grown to be more than just me receiving medicine. I now observe the other visitors in the infusion center. I am usually there longer than anyone else so I get to see at least a dozen or so people come in and out to get various treatments. I have talked to many of them. Most have cancer or some type of blood disorder. Being there reminds me just how much MS sucks. But seeing and conversing with other people struggling with ailments helps me remember, it could always be worse.
