Taking Control of Your MS Medication Intake

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Regaining Control of Your MS Treatment

Being diagnosed with multiple sclerosis is a lesson in loss of control. You are not in control of preventing it from being a part of your life. You cannot control when or how the next relapse will occur. You cannot control the fact that you are now at the medication station and you are never allowed to leave.

Sounds pretty bleak right? Maybe that is why so many people choose not to take their medicine from time to time, or in some cases, choose not to take their medicine at all. Like a child who won’t eat their vegetables, skipping meds can feel like our only outlet of control. And also like skipping your veggies, skipping your meds is not healthy.

However, I am not saying that you should forgo all control over the medicines you put into your body. On the contrary, I believe that you should harness all the control possible when it comes to dealing with your meds. It is something that needs to be looked at seriously and often.

Once you are diagnosed, it is necessary to have a detailed conversation with your neurologist about the drugs that will be prescribed to you. It is necessary to have a conversation at every visit to recap and tweak any prescriptions or change medicines completely. Your doctor is a great resource and is there to answer any questions that you have.

I have a method to deal with my medicines. I have three categories for them:

- Relapse treatment
- Disease modification
- Symptom relief

Having a compartmentalized system for dealing with my meds showed me how I could regain control over my treatment and my life by making careful, well thought out decisions. I have been freed from the burden of the piles of pills that used to throttle me until I would finally just drop them without physician supervision. I no longer deal with my meds with reckless abandon.

Relapse Treatment

Let’s look at the relapse treatment category. Firstly, I am one of those people who is quick to seek out treatment for my relapses. I believe that the faster my doctor sees me and gives me medicine to put in my system the better! I am sure you are all familiar with the protocol. First-time events are usually a five day IV steroid infusion and a full brain and spine MRI (with and without contrast).

Subsequent relapses can involve a myriad of routines depending on your doctor and how you are progressing. For me, they give me three days of IV steroids and a full brain and spine MRI (with and without contrast). I hate the steroids, but I am at every treatment and on time. My way of seeking control in this situation is by not allowing the nurses to leave in an IV port for the duration of the treatment.

They always say that it will make it easier for me in the following days, but I always say no. Truth is, if I had a port left in my arm then I would be thinking about my steroid treatment for the entirety of the three days. I would also have a freaking needle in my arm for three days that I would have to make considerations for when washing, changing clothes and basically any time I needed to move my arm or hold something.

I believe that the port in my arm would make their jobs easier, but I would much rather get poked with a needle three times than have one installed in me, thank you very much! I speak to the nurses much more politely though. I take a breath and say, ‘No, thank you,’ and then I stare at them smiling so that they know not to press the issue further. The key is to get the treatment that is necessary for your body to thrive and sort out the stuff that is unnecessary.

Next page: disease modification and symptom relief.

Disease Modification

Now let’s look at disease modification. It is necessary for you to choose a medicine that will reduce the number of relapses you have in the future. Those of us who are fortunate enough to have the Relapsing Remitting type of MS have a large range of medicines to choose from.

Things change so quickly with the treatment of this disease that I really think there's no point me listing which meds are out there right now. But I will say there were only a few MS injections to choose from when I was diagnosed eight years ago, and now we have both injections and pills to choose from. If nothing on the table strikes your fancy, you are able to join any of the multitude of clinical trials that are out there currently.

My point is, it is up to you to look at all of the options you have for reducing relapses and take control over medicine delivery method, side effects, effectiveness and dosing times. It is your job to look into yourself to decide what you will be most comfortable taking and sticking to on a regular basis.

I waited a year and a half before starting my disease modification therapy. I hesitated because I was scared and I didn’t want to commit to taking medicine for the rest of my life; a lifetime of medication is a daunting prospect that no one looks forward to.

Taking your MS medication can feel like you are welcoming this disease into your life. I promise you that the opposite is true. Starting your medicine and taking every dose means that you are fighting hard in a war that was thrust upon you. You are a warrior and you are in charge. Do not forget that!

Symptom Relief

Finally, we can talk about symptom relief. This is where I give you carte blanche! When you have a relapse or when you feel like you need long-term symptom relief your doctor may provide a myriad of medicines that help you in any number of ways. You can take all that your doctor hands you or you can forgo them completely. Just remember to have an open and honest conversation with your doctor when you do it. It is important that you are given what you need in order to feel better, but some meds cannot be safely dropped cold turkey.

I was given anti-seizure medicine during my first event. It was supposed to take away the pain of pins and needles that I was feeling all over my body. Three weeks passed. I took the medicine as it was prescribed, but I was not feeling any relief. I decided the medicine was useless and threw it away. Did you know that dropping an anti-seizure medication, without stepping it down properly, can actually cause you to have seizures? I didn’t. It was an important lesson for me. I learned that some medicines are not going to work. More importantly, I learned that it is deeply necessary to talk to my doctor before dropping a med!

Living this life with multiple sclerosis is an intense thing to do. But I really believe, to the bottom of my heart, that we all have the capacity to carve out our own story within it. We can create a space for ourselves that is unique and beautiful. We have to search more. We have to communicate more. We have to teach more.

Most importantly we have to define what our experience within this world will be like. Take control where you can and continue climbing towards more.