

My 2nd Maintenance Dose Of Spinraza

I woke up around 6:00 in the morning on Monday, July 9th. My second maintenance dose of Spinraza at UT Southwestern Medical Center's, William P. Clements Jr. University Hospital was scheduled to start at 1:00 in the afternoon. I woke up early so I could gather my thoughts before starting my day.

Even though I wasn't scheduled to check in at the hospital until 11:30, I got there around 11:00. I've always said that if you get there early, they would probably take you early, and this is exactly what happened to me.

After completing the paperwork during the check-in process, one of the nurses came out and took me to my room. Once I got in the room, two other nurses came in, and as one of them began asking me all of the usual questions, the other two nurses were getting everything ready so that they could take a urine and blood sample from me.

After answering all of the presurgical questions, and as one of the nurses began taking my blood sample, the student doctor came into the room and introduced herself to me. As the nurse began drawing my blood, the student doctor told me that she would be assisting Dr. Stehel during the procedure. She was a senior resident with only a year left before taking her boards to officially become a doctor.

My 2nd Maintenance Dose Of Spinraza

For those of you that don't know, UT Southwestern Medical Center is a teaching hospital. The student doctors are the ones who actually perform the procedure. Dr. Stehel's student, Dr. Sandra Schmidt, would be performing my procedure, but Dr. Stehel, the attending doctor, would be in the room to give her pointers and to ensure that everything was done properly.

After Dr. Schmidt left the room, and after the nurses finished taking my blood and urine samples, they transferred me from my wheelchair to the bed. Since I had about one hour before my procedure was to begin, I took this opportunity to shut my eyes and take a cat nap. At approximately 12:50, a nurse came in to take me to the fluoroscopy suites. Before leaving my room, I asked the nurse if she knew where my Spinraza was. She told me that they had already retrieved the Spinraza from the pharmacy, and it was in the fluoroscopy suite that I would be in, warming up to room temperature.

NOTE: In a previous video, I told everyone to make sure that your Spinraza had time to warm up to room temperature before doctors injected this into your central nervous system. If you get to the fluoroscopy suite, and your Spinraza is in the room, this should be plenty of time for it to warm to room temperature.

My 2nd Maintenance Dose Of Spinraza

As the nurse wheeled me into the fluoroscopy suite, the first thing that I did was to eyeball my Spinraza to make sure that it was already in the room. Even though the nurse had already told me that it was in the room, I just wanted to make sure for my own reassurance. I've always lived by the rule to trust, but verify.

After getting in the fluoroscopy suite, three nurses transferred me from my bed to the fluoroscopy table. As the nurses were positioning me on the fluoroscopy table, Dr. Stehel and Dr. Schmidt came into the room. After I had been properly positioned, Dr. Stehel took a fluoroscopic image of my back to make sure that nurses did not have to move me on the table. Once Dr. Stehel was satisfied with my position, and that he knew that the opening in my spinal column was in the correct location, he told everyone that he and Dr. Schmidt were about to begin.

As Dr. Schmidt took her position behind me, Dr. Stehel told her exactly where to inject me with the lidocaine to numb my back. After what felt like a small bee sting, Dr. Schmidt continued to give me lidocaine until she had properly numbed my back. After numbing my back, Dr. Stehel gave Dr. Schmidt a few final pointers and instructions. After listening to the instructions from Dr. Stehel, Dr. Schmidt began inserting the needle until she reached the central nervous system.

My 2nd Maintenance Dose Of Spinraza

It only took one minute for Dr. Schmidt to insert the needle all the way into the central nervous system. As soon as she was in the central nervous system, Dr. Schmidt told Dr. Stehel that she was already getting CSF, or cerebral spinal fluid.

Note: I have never had a doctor get into the central nervous system as quickly and smoothly as Dr. Schmidt had done. I was very impressed at how she took the instructions from Dr. Stehel and had managed to get her way into the central nervous system so quickly. To be honest with you, I think Dr. Stehel was impressed as well.

The beginning portion of the CSF had a small tinge of blood, but as she continued to withdraw more, the CSF quickly cleared. After only three minutes, Dr. Schmidt had withdrawn 5 mL's of cerebral spinal fluid. After the CSF had been removed, Dr. Stehel began drawing up the 5 mL's of Spinraza. Once the Spinraza was ready to be injected, Dr. Stehel positioned himself behind me and began injecting the Spinraza through the needle that was already in my central nervous system. After only about three minutes, Dr. Stehel said that he was finished, and he removed the needle and instructed the nurses to wash my back and to put a Band-Aid on the puncture site.

My 2nd Maintenance Dose Of Spinraza

After the nurse washed my back and put a Band-Aid on the puncture site, the other nurses came into the room and transferred me from the fluoroscopy table back to my bed. After saying goodbye to Dr. Schmidt and Dr. Stehel, one of the nursing aides took me back to my room.

When I got back to my room, I looked at the clock and it was only 1:25. My four loading doses and my first maintenance dose took between forty-five minutes to an hour. My second maintenance dose took less than thirty minutes. It felt like I was in a NASCAR race. Once I got in the room, they put me on the table, changed my fluids and then put me back in the race. The only thing that I knew was that my second maintenance dose had probably been the easiest procedure out of all of them.

After getting back in my room and lying flat on my back for an hour, nurses came in and transferred me back to my wheelchair and I was allowed to go home.

I had no side effects from the procedure for the rest of the day. Since I woke up early that morning, I decided that I would go to bed early. At around 7:45 in the evening, I hit the proverbial brick wall. I started getting a migraine headache and a feeling of nausea rushed over my body like a warm blanket.

My 2nd Maintenance Dose Of Spinraza

Doctors will tell you to drink something with caffeine if you start getting a headache after your Spinraza treatment. I had my caregiver make me a large cup of black coffee, and after about thirty minutes, my headache began to get better. For the nausea, I took three tablets of activated charcoal. Once activated charcoal gets into your stomach, the charcoal will absorb the acid that is causing the nausea.

Doctors used to give activated charcoal to patients who overdosed on drugs. The charcoal would absorb much of the toxins caused by the drug overdose. Activated charcoal tablets do the same thing with the acid in your stomach.

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My Recommendations To You

Ask your doctor to see if they would allow you to take activated charcoal tablets if you start to get nauseated after one of your Spinraza treatments. Also, check with your doctor about drinking a cup of black coffee as well. The caffeine will help to open the blood vessels in your brain. Headaches are usually caused by the narrowing of blood vessels. The caffeine will open these blood vessels up wider, allowing blood to flow more freely, thus helping to reduce the chances of getting a headache.

From now on, I'm going to drink a large cup of black coffee when I get home from one of my Spinraza treatments. My headaches started when I began my maintenance dose injections, so I'm hoping that drinking a cup of black coffee will help eliminate the possibility of getting a headache.

WARNING: Please remember, before following any of my recommendations, please consult with your personal doctor to make sure they clear you to take caffeine for headaches or any kind of activated charcoal products for nausea. They may recommend you take something else to help with these symptoms.