

Call me Johanna – A day in the life of an MS patient

Call me Johanna. I am living with multiple sclerosis, and today at 10:30am I have my annual MRI to check on the progression. I have taken the day off, because the hospital is about an hour's drive away from my home. I always have to calculate some waiting time, and the exam takes 45 minutes. I have relapsing-remitting MS and luckily I am still 100% mobile so I can manage everything by myself. It is 7:30 now, and my family has already left the house, so I can enjoy a little time by myself before hitting the road.

At 9:30, I get into the car. At this time the traffic is horrible and I am worried about being late, even though I left the house on time. I do not know if they will still take me if I am late. I waited several weeks for this appointment. You never get MRI appointments without booking well in advance. Even for my first one, I had to wait three weeks, although it was quite urgent because I lost sight in my left eye. I was diagnosed as having optic neuritis and tests already hinted at MS, but the MRI was inconclusive. In the meantime, I was treated with cortisone. Why do I always have to think of this first MRI again on my way to the MRI machine? I like to call it the 'tube' because of its tube-shaped gantry. It was ten years ago but the memory does not stop coming back.

I find a good parking place and enter the hospital. The queue for registration is not too long. Fortunately, the hospital has introduced a computer system where you just have to enter your insurance card details to register. In return you get a printed ticket which confirms your appointment and tells you where to go. Why does the radiology ward have to be in the furthest corner of the basement? It takes me another ten minutes to get there. Less mobile patients than me would need even more time. I take the lift downstairs. As always, the corridors from the lift to the radiology ward give me the creeps. No other patients, no staff, no windows. This place must be irradiated.

But as soon as I enter the waiting room, it is crowded. The assistant behind the desk is on the telephone and doesn't look up. So I smile at her and try to get her attention. But she only looks up after she has finished her phone call. She takes my registration form and asks me to sit down until I am called. I brought my book because I'm not interested in the old magazines in the waiting room. I start reading and waiting.

The radiologist calls my name. I am sent to one of the small changing rooms where I have to undress, remove hairclips and jewellery, and put on a gown. Before entering the room, he gives me a form that I have to complete while waiting, until he calls me again. I fill in my personal details and confirm that I do not have any metal implants in my body, I am not pregnant, and that I do not suffer from any other disease, etc.

The radiologist calls me again. I enter the small windowless room that holds only the 'tube' and some technical equipment. Now I have to lie down on the bed of the 'tube'. They will take pictures of my head and my neck spine. The doctor explains the procedure and asks me if I am afraid of small rooms; fortunately, I'm not. For claustrophobics, this must be a horror. Now he places a needle in my vein where he will inject a radiopaque material during the MRI examination. He puts earphones on my ears to protect me from the noise, and he puts a device with a mirror on my head so that I can look into the room and not feel confined in the 'tube'. In my left hand, I hold a button that I have to press in case of problems. I already know this procedure and I do not feel as uncomfortable as the first time. The doctor leaves the room and tells me he will be right next to me in the small room behind the big mirror.

The bed rolls into the 'tube,' and I am not allowed to move any more. As always, when the doctor tells me to try not to swallow, my saliva production gets kind of stimulated, and I have to swallow even more. But this only lasts a few seconds. Today, I am so tired that in spite of all the noise I am falling asleep. I wake up when the doctor tells me via the earphones that he will inject the

radiopaque material now. Suddenly, I feel the cold fluid running through my arm. I am thinking of previous MRIs. The first time, I was so afraid of the diagnosis, and I thought that there wouldn't be much time left until I would be sitting in a wheelchair if I really had MS. The noise of the MRI sounds like techno music, so I imagined being in a club dancing inexhaustibly, trying the whole time not to cry because then I would have to swallow. Today, ten years later, I am still able to dance and not afraid of MRI results any more.

I also have some exams where I really have difficulties not to move because of the pricking sensation I constantly feel in my arms and legs. The more I focus on the pricking, the worse it gets. The more I try not to focus, the more I focus. It is a vicious circle. These exams seem to last longer than the others, even though they really don't. Then I think it would be nice to get some music via the earphones for distraction.

But today I am quite relaxed. The exam is over quickly. The doctor takes me out of the 'tube' and removes the cannula. He says goodbye and that my neurologist will tell me the results. I already tried to get an appointment with the neurologist directly after the MRI to avoid having to go to the hospital twice. But the assistant told me that the results might not yet be accessible to the neurologist and that I should wait at least a day – another day of uncertainty. When I get a mammography the radiologist always tells me right away that I do not have to worry. The analysis of an MRI seems to be more complex. So I get dressed and go home.

One week later I have to take another half-day off, because I have my appointment with the neurologist to get the MRI results. It is the same procedure as the week before to get there. Neurology is not as frightening as the radiology ward. I do not have to wait too long until I am called by my doctor. He looks at the pictures and tells me that nothing has changed in comparison with last year's MRI. Thank god! But why did I have to worry for a week that new lesions might have appeared? And why did I have to come here again if I do not need any further treatment? He could have just sent me an e-mail as soon as he had access to the results.

I ask my neurologist if he could save the pictures on my flash drive because I need them for a request from the rehabilitation services. He says that the data is protected and that I have to address a written request to the radiology ward. Why do things have to be so complicated and tedious in modern times of data processing? So when I am back home I write a letter to the radiology ward and ask for my recent MRI pictures. I receive a disc with the pictures about ten days later. I am curious and put the disk in my computer. I cannot distinguish which white spots in my brain and my spinal cord are lesions and which of them just belong there. There are many white spots. This makes me feel slightly uncomfortable. But the doctor said there are no new lesions and I need not worry. So I close the pictures and try not to worry until the next MRI.