

## Balloon Compression Rhizotomies in Winnipeg with Dr. Anthony Kaufmann

I first travelled to Winnipeg for an emergency balloon compression rhizotomy on Boxing Day in 2012. I had recently been diagnosed with multiple sclerosis (MS) and learned I have at least two lesions in the area of the brain stem that caused the pain. I had serious allergies to the most effective medications (Tegretol and Dilantin) and was unable to control the pain with Lyrica, leaving me with no real option other than to have a rhizotomy. I had pain in the upper part of my face (V1) and mid face (V2) and pain triggers in the lower jaw (V3).



An additional complication for me was that the pain was on the right side of my face. The only procedure available in British Columbia is radiofrequency lesioning which can affect the reflex in the eye (cornea), meaning I could lose sensation and inadvertently damage the eye. As my left eye has very poor vision, losing my right eye would render me legally blind.

Unable to find appropriate and timely support in Vancouver, I asked my GP to refer me to Winnipeg. As a Canadian, the costs of the medical care are all covered. My out-of-pocket expenses included air fare and accommodation, and those expenses are tax-deductible. A balloon compression rhizotomy was performed on December 27, 2012, and I was pain free for sixteen months.

In that time, the nerve healed and repaired itself while the MS lesions in the brain stem likely left permanent scars. When the symptoms recurred in late April 2014, my neurologist asked me where I wanted to be referred for possible surgical follow-up. I had had such a good experience with Dr. Kaufmann and his team in Winnipeg, I asked to return.

Over the next four months, I was able to manage the pain with medication. By late August, I suddenly started having more and more pain, and tried to stay on top of it by increasing the Lyrica. I contacted Dr. Kaufmann's nurses, and we discussed my options. As they are all experts on TN pain (and the more severe TN pain associated with MS) they knew that we needed to move quickly. I am so fortunate that I was able to have surgery scheduled within three weeks of the pain worsening.

My husband, Daniel, and I arrived in Winnipeg on Sunday, September 14, and the next morning we had our pre-surgical appointments with staff at the Winnipeg Health Sciences Centre and department of Neurosurgery. We

checked in at Dr. Kaufmann's office and quickly saw Dr. Kaufmann along with a surgical resident. We had made the decision to proceed with another balloon compression rhizotomy as the MS has been relatively stable and a more invasive procedure (Dandy procedure) could be held off for another time if necessary.



Later, I met with anesthesiology, and we ended the day with Olive, a specialist nurse on Dr. Kaufmann's team. One of the best parts about working with this team is the direct support from the nurses once the decision is made to proceed with surgery. As my pain accelerated so quickly from late August and my needing to keep on increasing medication to stay on top of the pain, it was a life line to know that they were there for me.

On Tuesday September 16, surgery day, I had more pain that felt like a knife digging in my mid-face. I took my medications with small sips of water. I was relieved we were so close to the surgery time. We arrived early at the hospital and went to the Admitting department and they escorted us to the outpatient surgery ward where I got changed.

After administering antibiotics and steroids by IV, I waited until they came for me to take me to the pre-op area. I spent a fair bit of time in the pre-op area as Dr. Kaufmann's previous surgery must have been longer than anticipated. My surgery had been scheduled for 11:00 am and they came to get me just after noon. I asked the nurse in the OR if she could thank Dr. Kaufmann for me as I was so pleased to be helped as quickly as I had been. She



assured me that she would, put the mask over my face and told me to take a deep breath, then took it off. She told me Dr. Kaufmann had just walked into the room so I could tell him myself. He came over and smiled at me, took my hand and listened to me as I expressed my gratitude. I wanted to thank him ahead of time, just so he knew that I was grateful, even if the surgery didn't go as well as we all hoped, as there are no

guarantees and some degree of risk with each procedure.

After arriving at the outpatient surgery area, Daniel was waiting for me. He told me that Dr. Kaufmann talked to him right after the surgery and explained that he got good inflation of the balloon indicating there was no significant scarring of the nerve from the last procedure

I spent the night alone on the ward. Daniel arrived at 5:00 am to take me back to our hotel as they needed all the beds for day surgeries. They removed my IV needle, gave me a prescription for Valacyclovir to help manage an expected herpes outbreak, and discharged me.

The day after I was discharged from the hospital, I had a follow-up appointment with Dr. Kaufmann. For such an accomplished surgeon, he is not the least bit arrogant. He is gentle, warm and kind in personal interactions. I've seen so many doctors over the past four years and it's rare to find this combination.



We spent some time talking about the next steps in the management of the pain. He hopes I get many years of pain relief from this procedure. Seeing how well I responded this time, he says we could repeat it or try the Dandy procedure where he would go in behind my ear and into my skull, then cut 2/3 of the trigeminal nerve just outside of the brain stem. It's more invasive but he has done it about 15 times for people with MS and he never hears from them again.

I told him about some of the difficult times at home and with some doctors here in Vancouver. He has heard many of these stories before. Many of his patients get admitted to psychiatric facilities before finding their way to him and some surgical relief from pain. He was not surprised to hear that I knew more about what I was suffering from than most of the doctors I saw, including neurologists. I believe that's why his team is particularly responsive to any of us unable to get help through the labyrinthine and slow referral systems set up in each province.

I took a dose of Valacyclovir just before we went in to see Dr. Kaufmann as I was starting to feel the onset of a herpes outbreak. The last time I had a large outbreak up my face and into my nose. This time, the outbreak was smaller and healed much more quickly.

My face is much numb this time than last time. The numbness is very dense and goes from my lower jaw up to the crown of my head. The right side of the roof of my mouth and the right side of my tongue are numb, making it a bit more difficult to speak clearly. That has improved a lot over the past few weeks – lispng is mortifying for a speech-language pathologist! It sure helps me appreciate how much we depend on intact neurology for clear speech! I had more problems with food dribbling out of my mouth and opening my jaw wide. Chewing was very difficult for the first couple of weeks but it has been getting better and less exhausting to eat.

I have some strange sensations in my face, including the odd shock in the lip or the feeling like I am walking through cobwebs. These sensations have been settling a bit and I'm hopeful that I can start to enjoy life with renewed energy over the next month or two.

I am grateful to Dr. Kaufmann and his remarkable team, Olive, Michelle, and Andrea who heard my cry for help and responded quickly and compassionately. Knowing that they'll be there for me in future if I need them helps me a lot. Above all, their care was full of human kindness. For that kindness, I will always be grateful.