Living with Acromegaly Requires a Good Friend

I am a 46-year-old male with acromegaly, which I have had for 25 years. This is my story.

When I was a lot younger, my health was not too bad. I had the same doctor all my life up until two years ago. Looking back, I would have to say my old doctor was old school. Sometimes I get mad because he did not find this medical problem a long time ago. I had gone to him when I was bleeding, or if I had back pain, or something like that.

When I was in my teens and twenties, I was a big boy. I could wear a size 12 shoe, but I could not make shoes or boots last over three weeks, before the sides would be out of them. I did not think anything was wrong as some footwear you buy fits better than others. Now I wear a size 14-6E shoe and size 18 work boots because the work boots have to be CSA approved and CSA approved work boots are only available up to a size 5E.

My hands are a lot bigger than they were in my teens. It has been hard dealing with all this as of late as stores in the city do not have gloves that fit me. My wife and I spend a lot of time trying to find work gloves and boots. In fact, I cannot get work gloves in Canada, or the US, or so I have been told, over and over.

I found out that I have acromegaly in 2007, when my long time family doctor had retired and a replacement doctor took over. I was having some back pain and my hands were sore, so I went to the new doctor. He took one look at me and could tell that I might have acromegaly. He did not ask why I came to see him, but he told me a story about Andre the Giant, and what made him so big. My new doctor said he would like to have some tests done for me to find out if I had acromegaly. I left the doctor's office in shock, went home, and told my wife what this new so-called doctor/quack told me and how he would like me to have blood work done to test for this acromegaly thing. I told my wife that I would not be going back to the quack's office!!

I delayed getting my blood work for two months, partially due to my work schedule, but mostly due to disbelief. Finally, to satisfy my wife, up I went to get the blood work done and over with. Much to my surprise, a few days later, I get a phone call from the quack's office to say he wanted to see me in his office ASAP. The doctor told me my "growth hormone level is way up", and "I need to send you to see an internist as soon as he can fit you in."

About a month later, we were on our way to the internist's office. After a very thorough examination he agreed with my doctor's suspicions. I had to have an MRI and more blood work, this time to check my IGF-1. I took it hard and had disbelief when the MRI and the IGF-1 blood test came back. My IGF-1 was 480 and should have been 252 or less, and it was explained to us about the pituitary tumour and how it had been affecting my body for probably 25 years.

Next step was off to the city for a consult with a neurosurgeon and an endocrinologist team for more poking and prodding. Surgery would be done as soon as possible, although with a waiting list it could be awhile.

In the 4-5 months before the surgery actually took place, I experienced major headaches, double vision, and a lot of pain throughout my entire body. I suddenly became more aware of every pain my body was experiencing, whereas before I took painkillers and just tried to get thorough the day. The pain seemed to be changing and becoming more intense.

Finally, the call came to be ready in two weeks to go for surgery, but not before more blood work, another MRI and a CT scan. It was a little embarrassing to travel from one hospital to another with "Frankenstein-like" markers on my head and to travel home again with the markers still in place. Needless to say, I did not sleep well that night.

The surgery went well, and surprisingly, for the first time in months, I had no headaches and was discharged within 2 days. When I was on the drug "Cortef" and was quiet at home, I felt pretty good. Travel was not a good experience, since I experienced headaches, while riding in the car.

I did not know until much later, at my family doctor's office, that just prior to surgery, my IGF-1 was 1020. Since the surgery, I have complained about head pain. The head pain is not like a headache, but more of a feeling that I have been hit in the head with a hammer. I went back to work where I had to wear a hard hat all day long. The head pain got so bad, that I had to miss a lot of time from work. About nine months after returning to work, I had to leave work as I could not deal with the hard hat head pain, fainting spells, and joint pain. I just could not cope with these issues and keep working.

Five months after the surgery, I was started on a 90 mg dose of lanreotide (Somatuline® Autogel ®) by injection. My IGF-1 went down to around 380. My dosage was then increased to 120 mg. After 5 months on the increased dose, my IGF-1 went down to 295, but we still had about 7 months to go before our return visit to the clinic. We anticipated a good report after the progress which I had already achieved. You could have knocked me over with a feather when the endocrinologist told us my IGF-1 was 283 and still too high. The dreaded "R" word [radiation] was used. I wanted to explore other avenues beside radiation. However, with an increased dose of Somatulin Autogel not really being an option and pegvisomant (Somavert®) not being covered by my medical plan, the only available option is staring me in the face.

My life has changed completely. All the doctors and nurses at the VG in the city are great and work with me, with patience and understanding to help me grasp what I have to face next. They are the best, and have helped me deal with my acromegaly. I have increased pain four days before and four days after my needle, which I get every 28 days. Now I am waiting for more testing. Don't get me wrong, I know that I do have acromegaly, and I do love life, and want to live a long life with my wife. She is my best friend, and has helped

me deal with all this and it has been hard on her too. I hope that when you read this maybe it will help you understand that no matter how bad it gets, I know how you feel and you are not alone, living with acromegaly – you are special.

The nurses at the clinic have helped to start a support group for people with acromegaly. I find the meetings really help me to get through the next six months until the following meeting - just the knowledge of knowing that I am not the only one. I can look around the room and see other people just like me and know these people completely understand what I am going through - all of the other emotions and decisions and pain. I am truly thankful for each and everyone. Have a great life!

Clinical Pearls

- Radiation therapy is recommended when growth hormone levels do not come back to normal following surgery and medication.

- In our centre, we use stereotactic radiation (SRT). A single radiation fraction is delivered to a small tumour target. Patients generally require 25 fractions or treatments.

- The IGF-1 levels reduce very slowly and it may take up to 10 to 15 years to see the desired results. Patients may also develop hypopituitarism and require replacement of other hormones.