What can be revealed when you listen to your patients

You may wonder, "What in the world does this man know about type 2 diabetes (T2D) and toe injuries?" Well, I have had a very lengthy and lived experience with T2D. I was diagnosed 19 years ago, and I was very likely one of the worst patients with T2D ever.

How did I get here? How did it come to this? What is this? This is a problem with my feet that I will battle with for the rest of my life. This is an ongoing wound on my left large toe that a dear friend and I caused nearly 9 years ago that has never completely healed and now causes me to visit the diabetic foot clinic at the local hospital every 2–3 months.

Nearly 8.5 years ago, I did not know that this clinic even existed. I learned this fact, literally, by accident. Actually, it wasn't an accident; I learned through what some might consider performing a really stupid act.

My story

Picture it – on 13 January 2008, there was a man named Marty Enokson, someone who suffered from the chronic disease of obesity, as well as a myriad of other chronic diseases and issues, including T2D, high blood pressure and high cholesterol. He had suffered a mini-stroke 4 years earlier, he had reached a top weight of 505 pounds just 3 months earlier in October 2008, and he was about to receive incredible life-saving bariatric surgery that he so desperately needed. All seemed normal that day, but little did I know that things were not going to be normal. Nothing in my life has ever been NORMAL.

My bariatric surgery – the most complex and invasive surgery – did not quite go as expected. Unfortunately, after an 8-hour surgery, it was determined that I very likely had a leak. A leak was confirmed the next morning after a barium swallow, and at 4 pm that day, I was hauled back into the OR to fix a massive leak. Five hours of surgery later, the leak could not be fixed and my 84 day extended hospital stay began, while Mother Nature repaired what surgeons could not fix. She took her sweet time repairing me, I might add.

While I was in the hospital, I would walk the hospital corridors as much as I could to keep moving and to get some exercise and activity. Every time that I would go out to walk, I had extreme pain in my left big toe.

I would complain about the pain to the nursing staff, however the nurses could find nothing wrong with the toe. I repeatedly explained to the nurses that the pain was inside the toe – I remember them looking at me like I was nuts when I told them that. Every time I stepped on the toe it would hurt like crazy. There seemed to be no relief in sight.

One night, after walking for hours in pain, I came back to my room, and my dear friend Colleen Ellis was waiting for me. Colleen would stay with me, visit me, watch TV with me, and she would rub my back and my feet for me. She is an amazing friend, and she would do this for me almost every night that I was in the hospital.

On this night she was rubbing my feet and she advised me that there was a really big callus on my left big toe. I told her about the pain that I was having. We thought maybe that the callus was the cause of the pain. So while Colleen was rubbing my feet and toes, I told her to pick at the callus. I think it’s safe to say that you guys all know where this is going.

As she picked at the callus, it started to feel better, and the pain was beginning to ease. I told Colleen to keep picking at the callus. She picked, and she picked, and within a couple of hours, she had picked the callus to the point where she could get a grip on it to rip it out.

Colleen asked me, and in a moment of trying to deal with the immediate pain, and not thinking about the ramifications and consequences of this incredibly stupid decision, I told Colleen to rip it

Marty Enokson
Person with type 2 diabetes and a foot ulcer

This article is based on a presentation by Marty Enokson at Alberta Health Services Diabetic Foot Pathway Symposium, held in Edmonton on 1 June 2017. The key message was “listen to your patient”.

Marty agreed to share his journey with living with type 2 diabetes and a foot ulcer.
out! And that’s exactly what she did. She took a firm grip of the callus, and she ripped that callus off, and, oh my goodness, did it ever feel good. And then there was the realisation that underneath the callus was an enormous infection. At that very moment, I felt vindicated. I was right – there was something wrong with my toe.

**A problem revealed?**
What was left after the callus was ripped off? Oh, a hole in my big toe that measured about a half an inch wide all the way around and about three quarters of an inch deep. It was a massive hole in my toe. Oh, and there was a really angry nursing staff on Unit 44 who did not appreciate me creating more work for them.

At first, I had tried to take care of dressing my massive wound on my toe on my own, on the sly, but how in the world was I going to get the supplies? Even more problematic was the fact that I was hooked up to a load of machines and tubes, and I looked like the Borg Queen from Star Trek.

Needless to say, I could not control the bleeding from my toe, and I ended up having to confess to what we had done and enlist the help of the nursing staff. So, now, they not only had to deal with why I was there in the first place – for a leak post-bariatric surgery – but now they had to also deal with this pesky toe issue that I had created. They were a bit mad at me. I still felt vindicated because there was an infection; they did not feel the same way.

I had been in the hospital for almost 3 weeks when Colleen and I had ripped off the callus. And post ripping off of the callus, I was in the hospital for another ten weeks. And in those 10 weeks, while I was in the hospital, the care of my foot was less than stellar. I don’t say this to be rude. I say this because I want to bring attention to the fact that, clearly, an entire hospital ward did not know how to deal with my diabetic toe injury.

I had been diagnosed with T2D in 1999. It was common knowledge on the ward that I had T2D – they were still pricking my finger and testing my blood sugars four times a day, every day, till the day I was discharged – but they did absolutely nothing for my toe, which did not get better the entire time I was in the hospital. They would clean the wound, but that is all they did. I did not know any better. I had no idea how important my feet and toes were as a diabetic patient.

**Finally, enlightenment!**
It was at the start of week 13 – the last week that I would be in the hospital. Miraculously, my leak had decided to stop leaking on day 83, but that is not why we are here. I digress – we must go back to the Sunday. I had a cover nurse who had not been on Unit 44 previously. She was assigned to me, so when she came in to see me, she checked my tubes, she cleaned and changed my dressings, and then I let her know that she also had to change my toe dressing. She didn’t know that she had to do that as my toe issue was not a part of my chart.

I remember that she had asked me how long my toe had been this way. I told her what we had done and that it had been this way for the last 9 weeks. She was beside herself. She couldn’t believe it. I didn’t understand why she was flipping out. She was really freaking out. So I asked her.

She told me that she had worked in the diabetic foot clinic downstairs in the hospital. Once she calmed down, she explained to me that my toe wound was a classic presentation for neuropathy in the toes as a result of having uncontrolled T2D. Furthermore, she couldn’t understand why I hadn’t been referred to the diabetic foot clinic, which was housed in the outpatient services area of the hospital – only four floors down in the same hospital that I had been staying at for the last 13 weeks. A clinic that has been held every Wednesday since the mid-1990s and is now held every Tuesday and Wednesday.

I was beside myself. I had been on this ward with this toe issue for 9 weeks, and no one knew that this clinic existed. I could have been getting treatment for my toe much sooner. This amazing nurse advised me that she would be setting up an appointment for me to have someone come up and see my toe. That was on the Sunday. On the Wednesday, a nurse from the clinic came to see me – 3 days before I was discharged from the hospital.

Little did I realise that my escape from the hospital would be short lived. I was admitted to the foot clinic right then and there and I was seen weekly at the hospital for my toe injury for the next 2 years.
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The aftermath

During the 10-week stay after ripping out the callus, the massive deep hole had not healed at all. In fact, that hole took more than 2 years to close up and somewhat heal. Aggressive treatments were provided.

I continue to attend the diabetic foot clinic nearly 8.5 years after Colleen and I ripped the callus off. We joke about it now from time to time, and we smile, but I remember, at the time, how frustrating it was dealing with my toe, week after week. There was a point when I said to the physician, “Just cut the freaking toe off.”

Did you know that you really need your big toes and that they provide you with much needed balance? Who knew? I certainly didn’t. The physician advised me that cutting my toe off was not an option and I am very happy to report that I continue to have all my toes. I don’t know how, though. Without question, in my mind, pulling the callus off my big toe was one of the stupidest decisions that I have ever made, and as a result there are serious consequences that I continue to live with to this day.

In fact, I will live with that decision for the rest of my life, as my toes will never ever be the same. I now need to take extra good care of my feet and toes every single day, as my toe never fully recovered. I observe my feet, I debride down the callus and take care to moisturise as I’ve been taught, and see the appropriate healthcare professional regularly. It’s a great deal of work. But it is necessary as the healed skin over where the hole once was is extremely fragile and is prone to breaking open when too much pressure is put on the foot or when a callus is allowed to build up. I still live; I still move; I still work, and I will deal with and live with the recurring damage to my toe for the rest of my life. The callus was caused by the poor circulation in my feet, which was caused as a result of my diabetes being uncontrolled for so long. Because I just didn’t care.

As a result of my poor management of my T2D, not only do I have poor circulation in my feet, I now have to wear specially designed shoes to help take the pressure off my toes – toes that, as you all now know, continue to require medical intervention. As well, I get to wear extremely sexy compression stockings, even when it is 30˚C outside, to help with the poor circulation in my legs. Needless to say, I take these complications as a result of my T2D, which was caused by my obesity, much more seriously now, and I realise that I am not invincible.

Lessons learned

I would have to say that if I had taken the time to better understand my T2D and not ignore it for so long when I was younger and thought that nothing was going to hurt me, I wouldn’t be where I am today.

The lesson for healthcare practitioners is this: listen to your patients’ complaints about pain so that they don’t resort to picking the calluses off their feet.
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