

My name is Adriana. I'll get right to the point: we're here because our current "system" (for lack of a better word) for treating TMJD is not only broken but it's fragmented, and patients are falling through the cracks and left feeling abandoned and alone.

These cracks are actually more like a huge gap or a divide between the fields of dentistry and medicine, and it is in this no man's land that TMJD patients find themselves. Hip and knee joints belong to medicine, where there are well established protocols in place, but the TM joint falls under dentistry. This causes all sorts of issues for us in terms of treatment, pain management and insurance.

It's our dentist that refers us to an oral surgeon, so our family doctor is out of the loop from the get go, meanwhile, they are the ones that are actually treating our symptoms YET medical doctors have no knowledge of TMJD, and round and round we go!

After my right TM joint was replaced with a Biomet device.....

And I'd like to add here that it was replaced because I was told the joint had fused. I don't recall any alternative options given to me. I was simply told

that the joint needed to be replaced and what it needed to be replaced with. He was the surgeon, who was I to question his diagnosis or treatment plan, I had no reason not to trust him?

After it was replaced, my surgeon deemed the surgery a success because the joint was functioning and my opening was acceptable. I was to come back in a year. When, in tears, I began to list my new, more intense symptoms and the fact that the pain killers I was taking barely touched the pain, he stopped me mid-sentence and said: you need to deal with those issues with your family doctor. In that moment I felt dismissed, ignored and devastated.

Go to my family doctor? What does she know about any of this? So, according to the surgeon the surgery was a success, but somehow I had to convince my family doctor and the insurance company that I was in MORE pain, and ultimately unable to return to work. But worse than that, was that the one man/doctor “qualified” to acknowledge my pain, to possibly “treat” my pain, had dismissed me and didn’t want to hear what I was experiencing!

What do I do now? To whom can I turn? Who will believe me? There was no one else to turn to in dentistry. Oral surgery is the last stop.

So, the patient is left to do the research, they have to fight for, and dictate, their own treatment, they have to find a way to manage their pain, they have to deal with the fact that every aspect of their life has been affected by “this”. And what is it really that we are dealing with? Muscle spasms, nerve pain, headaches, migraines, neck pain, biofilm, sleep apnea, poor diet, depression, job loss, quality of life issues etc. etc.. What fields do those issues belong to? The pain clinic? Psychiatry? Infectious disease? Sleep disorder clinic?.... And again, what do they know about TMJD?

TO WHOM DO WE TURN?

We need a comprehensive approach, a combined effort, a coming together or meeting of the minds, to address all aspects of this disorder. The medical and dental communities need to come together on this because TMJD is obviously BOTH a dental AND a medical problem!

We have learned, through the collective suffering of TMJD patients, that surgery should be a last resort, and that we should not count on it to help reduce our pain level, BUT when we are in unbearable pain, day after day, and another surgery gives us even a “glimmer” of hope for some relief, we will take it! We will take it if we are facing this alone, if we are facing it without the facts, if we are facing it without an alternative approach, if we have no other supports in place, we will take the risk. This is how desperate we are, because our pain is rarely managed well.

At one point, I found myself envying cancer patients. That feels even shameful to admit, especially since I watched my sister battle cancer for two years. She's ok now, which is really the point. With cancer, one way or another, the suffering ends. But also with cancer, the world stops for you. Meals are made for you, compassion and support come flooding in. Ribbons and marathons and foundations, are everywhere. No one would dare question a cancer patient's symptoms or pain. Our experience is vastly different. Ours is one of isolation, loneliness, little compassion, and little awareness.

TMJD has affected every aspect of my life: physically, emotionally, financially, psychologically, professionally, and it has affected my relationships, my passions, my independence, and at times my dignity. It cut me off at the knees and changed the landscape of my life, and what I imagined my life would be.

I have had to accept that, we've all have no choice but to accept that. It would just be a whole lot easier to do that if what we are experiencing would be taken seriously. If we would stop being dismissed and abandoned.

I have a dear friend who has endured 18 TMJD surgeries. Her "glimmer" of hope came in the form of bilateral rib grafts by a surgeon she trusted, who was trying to develop a protocol around rib grafts. She had already endured 15 surgeries by then, every treatment, every device on the market, experienced every kind of aversive side effect, and figured that if she rid her body of these foreign devices that perhaps her body could heal and the pain would subside. It seemed kind of logical....remove the problem. Well, you guessed it, she is worse off than ever. She has been on intravenous antibiotics for months now, with no end in sight. Her pain is

unbearable and she would like nothing more than to never wake up. They may have removed the devices but the biofilm left in her system, along with yet more muscle and nerve damage has meant that her condition continues to deteriorate.

I tried to find her a physiotherapist when she first got back from having the surgeries here in the states. There was no physiotherapist, qualified to treat TMJ, that would take her on after hearing her history. I also tried to find her a pain specialist. I contacted the Toronto Headache and Pain Clinic. They don't take patients that are on any kind of narcotic.? She needs a new family doc but is terrified to do so, afraid that a new doctor may take her pain meds away. Infectious disease tells her to go see an oral surgeon. The only oral surgeon left in Canada that's qualified to see her, given her history, is the same surgeon that implanted some of the devices that devastated her life to begin with.

Did I mention how dark it is in this "no man's land" that we're in?

In my own journey, I felt I could leave no stone unturned. At one point I decided to contact the company that manufactures the device that I

currently have. I had to know what they would say. I was directed to call a woman who is in charge of “global complaints”. I explained that, given my pain pattern, my physiotherapist feels the device is too big for my joint space, and that one of the screws is too long and has gone through my zygomatic arch and into my temporal muscle. She said that she had received more complaints about the size of the device. She said this would all need to be verified by the surgeon that put in the device. I explained that he was deceased, so she said she would try to expedite an appointment with another surgeon.

Too make a long story short, she never followed through, and when I called her on it she said : “I said I would “try”. When I asked her about the screw, she started to get irritated and simply said: “We just make the device; we’re not responsible for how they are put in”. She suggested I contact the company rep for the surgeon that operated on me, so I did. He flat out denied having knowledge of ANY complaints about the device whatsoever and suggested I see the same surgeon the Global Complaints rep suggested. The problem is that that surgeon is one of the surgeons that the company uses to train other surgeons, and uses as a guest speaker. I decided to save my money.

The last stone I turned over was to go directly to the surgeon who designed the device. He was surprisingly forthcoming about my issues. He admitted that biofilm is an issue, that yes, a screw appeared to be too long, the fossa seems to be pushing into my ear, and the device may or may not be too big (he didn't really know anything about that).

His conclusion was that even IF the device is too big, and the screw is too long and the fossa is pushing into my ear, and biofilm is an issue, what are my choices? He said that surgery for me just wasn't an option; I would ultimately be worse off. He suggested I take antibiotics when the biofilm flares up and sent me on my way.

Don't get me wrong, he's right about surgery not being an option, and I'm glad he didn't suggest it, but again.....now what? I have to now somehow educate my family doctor on biofilm? I have to explain to my doctor about the fossa and the screw in the hope that I get adequate pain management? He really has to just take my word for it. I happen to have a wonderful family doctor, but I too fear a day when I may have to get a new one. I just can't imagine breaking in a new one....re-educating them on TMJD and the

side effects of my device. What if they're less empathetic, less "open" or willing to take my concerns seriously, or my pain seriously?

What is happening in Toronto is happening throughout the world. The confusion, frustration, isolation, lack of understanding – everything I described. It is clear to us the patients that the field of TMJ needs drastic change, among which are increased research, education, awareness, but more importantly the entire health care community needs to be educated about the complexities of this condition. The silos between dentistry and medicine need to be shattered. We can no longer be isolated from one speciality and another. This is dangerous for the patients!