Major Life Altering Metal Allergies

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I'm sharing my story in the hope that the *"Standard of Care"* in the medical profession will change, so that allergy testing, prior to surgery with metal implants, becomes mandatory. At the same time, I'd like to help create awareness and be supportive to others.

I am a mother, wife, grandmother, daughter, sister and friend whose entire life as I knew it, ended. My career was in the legal field, I was passionate about exercise, loved water sports and being involved in my children's and my grandchildren's lives. I was very content, in good shape and healthy. Now I'm on disability, I've only recently started exercising again and have missed out on 9 years of activity with my children and grandchildren, not to mention all of my other loved ones.

At the age of 49 I had a uterus ablation for fibroids. I ran into my gynecologist's assistant a few months later and mentioned I was doing better but was sexually numb. She asked me to make an appointment that day. Before the doctor even examined me, he said, "I believe you have a lower back problem." He referred me to a neurologist and I had a consultation, the following day. She referred me to a neurosurgeon. It was confirmed that I not only had central canal stenosis, scoliosis, degenerative disc disease and arthritis in my back but also cauda equina syndrome; this caused my sexual dysfunction and is considered a medical emergency, as it can cause neurological and physical problems. The neurosurgeon said I had left it too long and didn't think I'd get any physical sensation back but he still operated, to stop it progressing to paralysis and incontinence.

As he was wheeling me into surgery I said, "I won't be allergic to the metal hardware, will I?" he said "NO".

Nine months later, June 2010, I had my cervical spine operation. I had 16 screws, 2 rods, a plate and 6 intervertebral spacers.

I stopped all pain medication and my pain management, after a few months. About two years later I noticed I was always super tired. I'd go from my bed to the couch. I wondered if I were depressed so I saw a psychiatric nurse practitioner. I started taking antidepressants. She also did blood work and found that I had hypothyroidism. That explained why I had gained weight within six months prior, when I'd never had a weight problem before.

My symptoms became worse to having a lot of pain again and vomiting randomly every day and night. I had chronic fatigue and anxiety.

I went back to my surgeon to ask if I could be allergic to my spinal hardware and he still said no. After researching my symptoms myself, in great depth, because the antidepressants were not solving the problems, I discovered that metal allergies can cause havoc to health. I asked my surgeon to humor me and refer me to an allergy specialist. He did and I was diagnosed with metal allergy/sensitivity, to all metals, including titanium. The allergy testing involved patch testing showing allergies to cobalt chromium, nickel, gold, silver, (all metal), in addition to many other things and a Melisa blood test result indicated a high sensitivity to nickel and titanium dioxide. I provided the allergy test results for my surgeon and he gave me the impression that the word "sensitivity", albeit being high, (on the Melisa test) was not as bad as if it stated positive "allergy" high.

The allergist put me on a nickel free diet for 2 months but it didn't help. I took my prescriptions and vitamin supplements to her and she said that there were several I couldn't take. I had (and still have) to call pharmacies to ask them to check the package insert for whichever medication I'm prescribed, to make sure they are free from metal fillers. (Such as titanium dioxide; this is often used as a whitener) Each pharmacy may use a different manufacturer, so if there is metal in the tablets, I call other pharmacies to find another manufacturer. If there isn't one, I have to go back to the doctor to find an alternative.

My husband and I cook in ceramic pans because metal leeches into food; and I use plastic utensils. I don't eat or use ingredients from a can or drink soda from a can, as I vomit it up within 10 minutes. I take aluminum foil off baked potatoes immediately or I vomit. My dentist replaced my mercury/amalgam fillings (50% mercury in each filling) and my crowns were metal bonded, so he replaced them with ceramic crowns.

My surgeon didn't feel comfortable about removing my hardware because he said the only thing to replace it with was other metals. I researched further and found a doctor in Florida who had patients with multiple metal allergies, so he used carbon coated implants to replace their metal implants. They were doing fine. My surgeon consulted with my allergist and the Florida surgeon but decided that he didn't want to go the route of using carbon coated implants as it meant using a different manufacturer to the one he used. I presume he also talked to his own manufacturer about it and they couldn't do the carbon coating process, as it's only available with certain spinal hardware companies.

I became progressively more ill over two more years. I ended up on pain medications (opioids) again, more than I'd taken after the operations; I had to have a pain management specialist and medical home care. I planned my death with my husband of 20 years, which completely tore him apart. He freaked out one time when he thought I had stopped breathing. Another time, I drove myself to an appointment as it was close to home and my husband wasn't available. He came home and called the police because he couldn't find me and he didn't think I was well enough to drive, yet the car was gone. He and two policemen were out looking for me. On really bad days, I remember thinking that I couldn't believe how much pain a person could live through, and that it didn't kill them/me. I didn't believe I had the option of going to the ER at the hospital. If my allergist, surgeon or any of the other medical doctors couldn't figure out what to do for me, I didn't believe the ER could either.

Finally, three years ago, I got to the point when I was on home care that my nurse came one day and said okay, now call your surgeon and tell him you haven't gone to the bathroom in a week. I called and that's when he said, "Okay, now your symptoms are overriding my concern for taking out the hardware." He removed it without replacing it, not knowing how I'd be. I instantly felt soooo much better! At my follow up appointment, my husband asked the doctor, "If you don't believe allergies were the problem, how would you explain how much better she's obviously doing?" The doctor said, "I can't". I was given the impression that he felt it was really rare. He hasn't changed his standard of care in his practice to prevent it from happening again. Yet, one day, I was in his waiting room and overheard one of his office assistants on the phone asking a patient "what makes you think you're allergic?" What are the chances of that, if it were so rare, right?

I still have 6 intervertebral spacers, that can't be removed. I have to watch what I eat; I can't take any medications containing metals and randomly but rarely, still vomit sporadically for whatever reason. Maybe from having a glass of wine now and then, which I just learnt today, has metals in it. Or, I just don't know.

One year ago, I had a lumbar nerve ablation. I try to go to the gym 5 times a week to strengthen my core and do cardio. It's helped a lot. I've noticed my back pain increases if I let more than two days go before training. It's hard though; I've had to maintain a mindset that if it's all I can do in a day, I HAVE TO at least try to go to the gym.

I've tapered down my fentanyl patch from 37mc to 12 and I'm not taking as much Norco. My goal is to come off completely; fingers crossed. Other things that still help are massage, Epsom salt baths and ice packs.

My thoughts on my experience and I'm sure others feel this too, is that being so sick and mostly homebound, causes a social anxiety. I have anxiety when I think about going out of the house and I feel socially awkward whilst I'm out. It's really uncomfortable. I even feel it with my friends and family. I was never the type to complain and they don't fully understand my whole story. It may seem as though I've purposely withdrawn, which has put an awkward strain on all my relationships, especially as I do not feel well enough to do all the socializing I did before. Also, it's because I cannot keep in touch so often which, to a certain extent, leads to losing connections. We don't get invited to family parties, get togethers, or other activities, as I find it difficult to stay for any length of time and sometimes, I have to miss it altogether.
So that still continues. It hurts my heart; I miss the life I had, terribly. By the same token though, I'm thankful to be doing so much better and thank God, I was fortunate enough to have my hardware removed. I know not everyone can.

I must express my appreciation for Rebecca Dutton for maintaining a support group, for her amazing empathy, kindness, resources she's found and shares, and what seems like endless hours of availability to even just "be there for me" for years! I'm ever so blessed to have met her on social network early on in my fight.

In conclusion, I leave you with my current hopes and dreams: that my experience should not be in vain; that I may somehow make a difference in changing the standard of care so more people don’t suffer in this nonsensical way; that I may be successful as an advocate in creating an awareness of metal allergies, at rapid speed. And for those who are suffering, I extend hope that they somehow feel my support as my heart goes out to them. May they all feel better soon.