

Meet Gregory...

Dear TMJA Members,

I recently published an essay called "*Empty House*" in the literary journal *AGNI* (No. 93, 2021) that meditates, in part, on how TMJ pain forced me to resign my professor position. In gratitude for all that The TMJ Association has provided me over the past 30 years, I wanted to share this with the members of The TMJ Association.



Here is the essay: <https://tinyurl.com/526rw4xd>.

It is around 30 pages and is presented as an illustrated "architectural memoir" covering the years 2000-04.

Since that time, I have shifted my teaching online where I work for various universities with few required talking scenarios such as Zoom lectures. This, and working with various specialists, has resulted in a fairly low-pain and pharmaceutical-free existence for me. I feel almost ready to try lecturing live again, and will be doing a little at McGill University in 2022. Note: I am not cured. Careful management of my TMJ situation will likely be life-long.

That said, I am grateful to The TMJ Association for their generous sharing of information, and advocacy for TMJ recognition and research--and especially for convincing me that surgery was not the best option for my condition. I was tempted, but glad I went the route of minimal physical intervention.

If you choose to read my essay, I would be very interested in any comments especially if this captured some of your own experiences. Feel free to direct message me through Instagram @infiniteshelter.

--Gregory Caicco

Two Different Fields, Two Different Experiences

We thank Lisa for sharing the following perspective and first-hand experience with our readers.

Over the last 20 years, I was unfortunately subjected to many surgeries due to my Temporomandibular (TMJ) conditions. I traveled across this great country seeking treatment for this extremely painful condition. I received many different opinions with vastly different treatment protocols. It was horrific to learn that I was in the midst of a debilitating condition that had very little scientific research or evidence-based medicine which could give me a sound treatment plan, one that would lead me out of my predicament. I found myself confused, lost and desperate for relief.

One theme that seems to be consistent across the country is that the surgeons are predominately male and the patients are largely female. My experiences brought sexism into the spotlight. I had oral maxillofacial facial surgeons who suggested I was a stressed-out young mother and this was mostly my fault. I also felt the conversations with these surgeons seemed to go more smoothly if I brought my husband into the equation.

A recent article interviewed Clark Stanford, DDS, Dean of the University of Illinois at Chicago School of Dentistry. The article states that it is estimated that 10 to 35 million Americans suffer from a TMJ disorder at one time or another with the largest demographic being pre-menopausal women. He believes this is the reason many women with a TMJ condition are overlooked. Dr. Stanford said, *"There could be a component of sexism in clinician's offices."* (Greenberg, Gary "Get Relief from Jaw Pain." Newsmax Magazine, October 2021 pg. 88)

With the TMJ surgeries I had, I felt I was treated with very little compassion. My pain was ignored and I was told to "deal with it." The first surgeon I saw suggested that I was mentally ill. He and the orthodontist would tell me to breathe when I came in, making me feel as though I was a psychotic crazy woman who was causing harm to her own body. They drove me into a state of depression and anxiety. The surgeons gave little care to the changes I watched happen to my face. After one of my surgeries, my lip became paralyzed. When I asked if the nerve would heal, I was replied with a shoulder shrug.

When I was admitted to the hospital after the major TMJ reconstruction surgeries, I found little help with pain management. The nurses did not understand the terrible pain these surgeries caused. They seemed more concerned about preventing me from becoming an addict than with lowering my pain so that my body could heal. The resident who was put in charge of my pain management in the hospital, gave me half of the morphine equivalent of medication that I was getting at home. This meant I was literally receiving zero pain management after a total joint replacement. I found myself crying to the nurses and pleading with them to let me die. I cannot express in words the level of pain I experienced with very little support.

Recently, I found myself in a new predicament. I was told that I might have endometrial cancer. The referral I received was to a male gynecologist at a high-rated clinic. I realized I was in a similar situation to my jaw surgeries; I was once again seeing a male surgeon

who treated only women. I went forward with the surgery and to my surprise my experiences were vastly different.

The gynecologist was able to give me data about my condition based on what he saw on my ultrasound. There was a set protocol for my condition that he followed and it was based on scientific research. Imagine my surprise when I realized he was following evidence-based medicine, rather than the chaotic approach I experienced with my TMJ disorder and continue to experience. I had a biopsy which was followed by a surgical procedure.

The day of my surgery the nurses were welcoming as they got me ready for the surgery. I had a meeting with the anesthesiologist prior to the surgery. I explained the jaw issues I had and how I was scared the intubation would harm me. He was so kind, and promised me he would take great care and he would not harm me. My surgeon came and went over the procedure and discussed what we would do for pain. He again showed great compassion and assured me I would be okay. He told me he did many of these surgeries, but said he understood that no one wants to go through surgery.

After the procedure, I woke up in recovery. A kind nurse was there giving me medication before I could ask for anything. She brought me some heat packs for the pain and kept me comfortable. She made sure my husband was aware that I was awake and doing well. My surgeon came and told me what he saw and that he sent the tissue to pathology and we would review the results at my follow-up. The pathology showed normal tissue and a polyp. Again, my surgeon was able to tell me that, based on scientific research, there was a 90% chance the polyp would not return and I would most likely not have problems in the future. He told me if I developed certain symptoms to contact him. I felt relieved and grateful.

It can be inferred from my experiences with my two conditions that my treatment and care were on polar opposite ends of the spectrum. Even though the TMJ surgeons and the gynecologist were all male, I was treated in a dissimilar way. One surgeon treated me with respect and dignity as a human being while others treated me as a stressed-out woman who caused her own condition. I hope the oral maxillofacial surgeons can understand this and change their treatment of women. We desperately need research to find the reasons why more women get TMJ disease, and surgeons need to stop blaming this condition on women. I cannot imagine a man being blamed for causing a health condition. It's past time to bring TMJ treatments and surgery into the 21st Century.

In the last couple of years patients have received some hope with the formation of the TMJ Patient-led Roundtable and the National Academies of Sciences, Engineering and Medicine's (NASEM) yearlong study and report on TMJ disorders. Gregory Ness, DDS represented the American Association of Oral and Maxillofacial Surgeons at the NASEM meeting where several patients shared their story. He said, *"To each of you, I say, I am sorry, I am sorry you continue to suffer, that we failed you in our promise to make you better not worse. I am sorry you heard foolish, ignorant, dismissive and carelessly cruel things from those that were supposed to care for you when you needed it the most. I am sorry that you had far more operations than one person should ever have, or that you very understandably don't know who to trust..."* As patients who have experienced injustices we hope for a future where patients are cared for in an equitable way with care,

Catastrophizing: A Form of Pain Shaming

The following excerpt is from a blog post by Gwenn Hermann on the U.S. Pain Foundation website that we thought would resonate with TMJ patients.

The first time I heard the word “catastrophizing” being used to describe the pain experience on a national level was at a chronic pain lecture at the National Institutes of Health. It sent shivers through my body.

After 25 years of living with chronic pain and 20 years working with the pain community as a clinical social worker, I have become an expert in the field and what it takes to fight to take back your life from intolerable, daily pain while creating a quality of life. I was horrified at the use of this pejorative word and voiced my reaction.

The response that I received was condescending and reflected zero knowledge of what it is like living in the body of someone with chronic pain.

Medical and mental health professionals in the field of chronic pain commonly use this terminology with each other and with their clients/patients. At best, “catastrophizing” is insensitive to patients’ very rational and reasonable response to the impact of pain on their lives. At worst, it perpetuates a harmful stigma and creates yet another obstacle to effective pain management.

[Click here to read the full blog article](#)

The “Problematic Patient”: What is the Problem?

We invite you to read a recent article by Prof. Dr. Jens C. Türp at the Clinic for Oral Health & Medicine, University Center for Dentistry, Basel, Switzerland entitled, *The “problematic patient”: what is the problem?*

In this article Dr. Türp presents this question and provides an illustration of temporomandibular disorders (TMJ/TMD). The article concludes, ***“dentists should live up to their responsibility and trust given to them by patients. For that purpose, dentists must be aware of their limits of competence and be cautious about overestimating their abilities. There are not only “difficult patients;” there are also “difficult dentists.”***

Click here to read the full article: https://www.online-dzz.com/fileadmin/user_upload/OA_Problematic_patient_01.pdf

Meet one of our TMJ Supporters...



Flying Aero Von Der RNR Ranch

"I'm a very special boy in that I get to go everywhere with my mommy, grocery stores, doctor offices, etc and I can push the button and the doors open. I help mommy by carrying things or opening the pantry or cabinet doors... and if I see mommy looking like she's sleeping at the table, I go over and gently put my head on her lap and lift her head to wake her up being extra careful not to hurt her face."

Submitted by Karen

The TMJ Association is planning to create a fundraising pet calendar and invite TMJ patients to send us a photo, along with a short explanation, maybe from the pet's point of view, of the significant role they play in your life. [Send your pet submission to info@tmj.org](mailto:info@tmj.org).

The TMJA is Here Because of You!

The TMJ Association (TMJA) is the only nonprofit patient advocacy organization fighting for the best science that will lead to a greater understanding of Temporomandibular and related disorders, as well as safe and effective treatments. **We cannot change the face of TMJ without YOU!**



If you are an employee of a government agency who understands the full impact of Temporomandibular disorders on individuals, their loved ones and society at large, please help us by designating The TMJ Association as your **Combined Federal Campaign (CFC) charity #12102**. Ask your mail carrier and those you know serving in the military to consider pledging their support to The TMJ Association. If they don't already have a chosen charity, they may be glad to help!

State government employees in Arizona, California, Connecticut, New Jersey, New York, Ohio, Pennsylvania, Washington and Wisconsin can also contribute through the State Employee Contribution Campaign by writing The TMJ Association on the donor form.

United Way and other nonprofit corporate donor programs are great ways to improve the plight of TMJ patients. Simply write The TMJ Association on your donor form.

If you don't participate in any of these campaigns, you can still help by donating directly to [The TMJ Association](#).

About The TMJ Association...*Changing the Face of TMJ*

The TMJ Association, Ltd. is a nonprofit, patient advocacy organization whose mission is to improve the quality of health care and lives of everyone affected by Temporomandibular Disorders (TMJ). For over 30 years, we have shared reliable information on TMJ with people like you. We invite you to visit our website, www.tmj.org.



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The TMJ Association, Ltd. is a nonprofit 501(c)(3) tax-exempt organization.

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