— A Story of Trigeminal Neuralgia —

My Struggles & Successes with the Suicide Disease

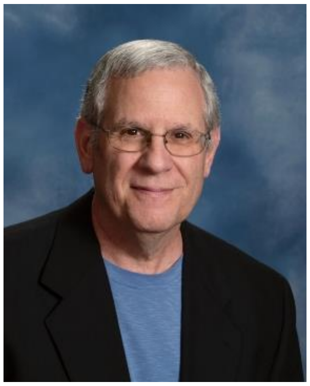
By Mark Dattoli • Elmhurst Illinois • 2020 All Rights Reserved

ARTICLE OVERVIEW. This is the account of my experience with the disease called trigeminal neuralgia (TN). I have had many significant ups and downs over the past 3 years with TN and am still wrestling through some things. It is my intent to share what I have learned (so far) about TN. Please understand that I am not a doctor and I am not dispensing medical advice. I will, however, share my research, personal experience, and opinions for what they're worth. It has been, and still is, a fascinating journey.

MEDICAL OVERVIEW. Trigeminal neuralgia is a rare medical condition that causes tremendous nerve pain in the face, usually on one side only. The pain occurs in episodic attacks that range from seconds to minutes and may occur dozens of times a day. They are often described as feeling like being struck by lightning, being stabbed with a knife, or having a live wire held to your face.

Researching TN results in a lot of bad news— • It typically takes seeing 3 specialists before an accurate diagnosis is made (and specialists can often take weeks to get appointments with); • TN produces the most excruciating pain known to man; • There is no known cure; • You will have it for life; • It will only get worse; • Over-the-counter pain meds (NSAIDs, etc.) are of no use; • Prescription meds may work well, but relief may only last until you develop a tolerance to them, and they may cause some horrible side effects for many people; • Surgical treatments are usually unpleasant, not always effective, quite risky, and of course, very costly; • With TN being relatively uncommon, the typical emergency room often misdiagnoses or mistreats it, and at best can provide only the briefest relief; • While some doctors now avoid calling TN the *suicide disease*, many who suffer "intolerable" pain for days/weeks/years do think about the unthinkable. Knowing these things and being diagnosed with TN can almost feel like a death sentence.

Clearly, TN sufferers are in great need of understanding, sympathy, and support. When I read people's stories on the Facial Pain Facebook page, it is usually very heartbreaking because I know what they are going through (to an extent). Yet there is some hope, and there are many things a TN patient can do. In this article, I share my experiences, both good and bad, so that TN sufferers may be helped, and those who love them can be more understanding and supportive.



The Author

Opinions & Ideas for People Who Suffer with TN

In these sidebars are details and tips that may be helpful for those who desire more technical and specific information.

FYI. The richest source of data regarding TN is the Facial Pain Association (https://fpa-support.org/). Under *Resources* you will find their wonderfully informative *Quarterly Journals*, as well as *Webinars, Documentaries*, and a *Support Network*. You can also join their Facebook page (search for *FPA*), see their *Tip Sheet*, and get their *Patient Guide*. A fellow sufferer, Mayra, also has a nice, well-researched website.

OPINION. Much of FPA's data on surgical options seems to focus on *GammaKnife*, which should be updated to *CyberKnife* (which I think is a better option)—more later.

MY TN STORY. In early 2017 life was good. At 67, I was a happily married, soon-to-be empty-nester, a retired IT management consultant, and volunteering as the executive director of a local, mid-sized church. I led an active lifestyle, took no prescription meds, and had good vitals. One morning in May without warning I had my first attack of TN as I was waking up in bed. It felt as if I had been lanced with a fishhook above my right eyebrow and was being pulled about throughout the house; it lasted almost 2 minutes. I had more attacks 4 or 5 times a week and saw my primary care physician a few weeks later, who didn't know what it was.

True to form, it took referrals to 3 specialists before a neurologist accurately diagnosed it as TN. During this time, my attacks became more frequent, and were triggered by shaving, washing my face, coughing, yawning, sneezing, deep breaths, and most consistently, the first bite of a meal or brushing my teeth.

My neurologist prescribed the standard first-line treatment protocol of an anti-seizure medication called Tegretol, which had an immediate effect and seemed to have stopped all attacks, to my great relief!

Prescription Medication

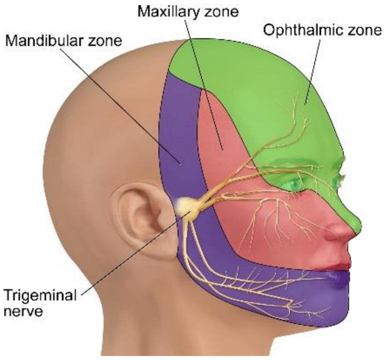
DIAGNOSIS. If Tegretol does stop attacks, that is usually considered further confirmation of the TN diagnosis.

TN TREATMENT. I started on 400mg per day of Tegretol (carbamazepine) and was also given a Complete Blood Count, CBC, panel so the doctor could monitor possible side effects.

SIDE EFFECTS. Shortly after I began this prescription, I developed pervasive skin irritation, especially on my scalp, as well as severe facial acne. I began regular visits to a dermatologist. Although my doctors did not think it was because of the Tegretol, I'm certain it was.

SKIN TREATMENT. For the itchiness of my skin I tried many prescriptions, most costly and not all that helpful. What did help me were these: Triamcinolone Acetonide Cream 0.1%, Metronidazole Topical Cream 0.75%.

For 3 months, Tegretol seemed to prevent all attacks, although my right eyebrow would feel pressure or a slight twinge at times (I interpreted these to be precursors, or warning signs of worse days ahead). Then, over the next 12 months, small, short attacks began to return. They increased in frequency and intensity during that time. The neurologist gradually doubled the Tegretol dosage and eventually added other prescriptions. Throughout this period, I tried alternative treatments as well, such as chiropractic adjustment of my jaw, acupuncture, lavender pills, increased magnesium/vitamins, etc. These alternatives provided no apparent relief. Neither CBD- nor THC-based treatments were yet in my thinking.



The Trigeminal Nerve

From Wikimedia Commons

How I Knew I was Ready for Surgery

After I acclimated to the maximum dosage of Tegretol, the doctor added Gabapentin and Baclofen; I do not think either of these helped at all. And what I believe to be side effects of the medications were becoming too much to bear. Not to brag, but I had always been mentally alert, quick-witted, articulate, analytical, productive, creative, and artistic. All of that was now gone. How I missed the old me. I lived in a perpetual zombie-like state—an empty head on a body that itched like crazy. And yet the TN attacks persisted and increased in frequency.

In late 2018 I was having upwards of 20 attacks per day. My neurologist considered a nerve block injection but instead decided to refer me to a surgeon he knew that did *GammaKnife* surgery at the University of Chicago. The fantastic articles in the *Quarterly Journals* of the *Facial Pain Association* helped me think through the surgical options and ramifications. I was not thrilled with the process of *GammaKnife*, particularly with the harness that is used to stabilize your head during the surgery. While I was pondering all this, I consider it a miracle that I ran into a friend at church who had coordinated the establishment of the cancer center at my town's hospital. In doing that, Sharon was instrumental in bringing *CyberKnife* to the hospital and in hiring a surgeon who was expert at using it for TN patients. As opposed to *GammaKnife*, *CyberKnife* uses a non-invasive, mesh mask for the surgery, which relieved my anxiety regarding that. My encounter with Sharon gave me the confidence I needed to proceed.

I was due to spend the last 10 days of the year at my in-laws which would be inconvenient knowing that the first bite of every meal would trigger a brutal TN attack. On December 10 I began the process of consulting with the surgeon, getting an MRI and a CT Scan, and getting fit with the mask. On December 21, 2018 I had the *CyberKnife* surgery done. December always seems to be a very busy time in hospitals when people have insurance deductibles that are covered for the year and they want to get elective surgeries attended to. So, it seemed like another miracle that I could get my surgery done within 11 days of deciding to do it. The in-law trip went much better because of having the surgery.

CyberKnife Equipment
From cyberknife.com

From civco.com

CyberKnife SURGERY. Nice overviews of this type of surgery can be found at cyberknife.com. The Spring 2018 *Quarterly Journal* of the *Facial Pain Association* also covers it well.

MY EXPERIENCE. I walked in, didn't need to change clothes or do any typical hospital pre-op stuff. I just laid down on the table and they put on the mask that we had created earlier. The mask was affixed to the table with no pain. With a couple minutes in between each, I had three 30-minute sessions as the robot directed the radio beams according to the surgeon's program. The only pain I felt was toward the end of the third session when the back of my head was tired being on the hard table; that was painful for the last 15-20 minutes. But then I got up, rubbed my head a bit, felt fine, and walked to the hospital cafeteria. I had tried to be as still as possible during the surgery because movement would cause the robot to stop until I became still again. Whenever that happens the surgery would take longer. I was told it would be 90 minutes at minimum, and mine took about 95 minutes.

POST-OP. I was very curious to see if the first bite of my cafeteria lunch would trigger an attack. And it did, but at a pain level of about 3 or 4, down from the usual 6 or 7. While this surgery is sometimes immediately successful, I was told that it's common for the relief to build up over time. So, per surgeon's orders, after a month I slowly decreased my meds, going completely off them after 4-5 months. Thankfully, my skin itchiness has also resolved, and now I only use an over-the-counter moisturizer—after trying many, I like Vaseline's *Extremely Dry Skin Rescue*, which is reasonably priced.

The second half of 2019 was wonderful with no TN attacks and no skin rashes or itchiness. And 2020 began well until February when a side effect of the *CyberKnife* surgery began to occur. In the consultation, the surgeon had explained the risks: Ten percent of the time it doesn't help at all; 10-20% of the time facial numbness or paralysis can occur on the side of the face operated on. I heard these warnings, but the promise of relief from this horrible disease made the risks more than acceptable.

In my case, I began to feel facial numbness, not just above my eyebrow, but the whole side of my face, from my forehead to my chin. (A technical note: There are 3 branches of the trigeminal nerve—going to roughly the forehead, the nose, and the chin. These branches come together around the temple, and it is there where the surgery deadens the nerve.) At times, my eye often feels like it has a spec of sawdust in it, while my nose feels like it is frostbitten, and my cheek and jaw feel like they have a second-degree burn. On top of that, the numbness results in frequent biting of my tongue and cheek. I'm able to eat only soft foods, it is often painful, and I can taste food only on one side. My upper and lower teeth on the right side often feel frozen, or as if they were made of wood. I've now learned that this is called *anesthesia dolorosa*.

With these constant pains, it’s impossible not to rub my face which provides relief while I rub. Nevertheless, early on, I must have rubbed my face hundreds of times a day. Then, along came the COVID-19 guideline to not touch your face! Now I do it much less but cannot totally stop.

Speaking to the surgeon, he explained that my facial numbness implies that enough of the nerve was deadened, so, to a degree, the numbness is good news because the TN will not likely return, as it might if too little had been deadened. He said that the bad news is that the numbness is likely to be permanent. My physician, however, said that it is possible that after a period of years (5 perhaps) it could subside as the nerve may regenerate. We will see, I guess; it would be nice. The surgeon also said that it won’t get worse, which I interpret to mean that my face won’t become paralyzed.

The problem I have now is that the numbness has become quite painful over the past 2 months. I rate it at a pain level of about 5, which is equivalent to a bad headache that is quite annoying (but not a migraine headache, which I understand can be debilitating). And the pain has been quite persistent throughout the day. I have at times wondered if a constant pain level of 5 is any better than the episodic levels of 7 or 8 I had before surgery; then I realize: *of course it is*.

My surgeon, my physician, and the literature agree that, at this point, there’s not much I can do to relieve the numbness. At first that was discouraging. But I was glad to discover that laying down, for some reason, reduces the pain. Sometimes a warm compress helps too. Lastly, two friends of mine, Gary and John, independently suggested I try a CBD-based product, and I have found a lotion that seems to be providing significant help, at least for now. I knew enough about CBD, THC, etc. to understand that CBD is not psychoactive (producing a “high”), and was legal, if not highly regulated/certified. And when I asked about it, my physician did support my use of it, saying that sometimes it can help with nerve pain.

FACIAL NUMBNESS. Luckily very few people have TN. And only a fraction of them have *Gamma*- or *CyberKnife* surgery. Then only a fraction of *those* develop post-op numbness to the point of significant, persistent pain. So even in the support network, I haven’t found others dealing with what I have. But what I am doing is this: A local CBD store let me try a couple different samples on different days. So, I then bought 4 different variants (a bit expensive but worth a try). I am now experimenting with them and finding that when my pain is at a level 5 and I apply a cream, after 10-30 minutes the pain seems to go down to about a 1 or 2. Sometimes I feel the need to re-apply a second time during the day; sometimes I seem to be able to go a second or third day before I need it again! I don’t have long-term conclusions about this experiment yet, and I am being cautious because I do not want to build up a tolerance against its relief.

COLD SENSITIVITY. With my face feeling frostbitten, somehow my body thermostat has been affected. Wintry weather is especially brutal, and I now use contact lenses when I shovel snow, so my facemask doesn’t fog my glasses. I can feel chilly even in 70-degree weather. Even a week in 85-degree, sunny Florida did not relieve the sensation.

ORAL CARE. Dental visits with TN can be scary/painful, and major dental work risky so I want to be as careful as can with my dental hygiene. But with my numbness it hurts to floss and brush, and it’s hard to tell what I’m doing. So, I am now using an electric *WaterPik Water Flosser* and an *Oral B 1000* electric toothbrush, both of which help a lot.

SOME REFLECTIONS. As I reflect on the past 3 years, I have these observations.

1. Doctors have often asked me to rate my pain on a 10-point scale which I never knew how to answer precisely. So I was glad to discover a helpful diagram that describes each pain level (by Alice Rich).
2. When I read the stories of others with TN, I am struck by how long it has taken some of them to be accurately diagnosed. While it did take 4 doctors for me, I felt blessed that twice when I called specialists, there "happened to be an opening that same day" instead of the typical 3-week wait.
3. While it has been a difficult 3 years to get to where I'm at now, I read stories of others on the support network who have suffered with it for much, much longer. When I read their stories, I hurt for them, and often take a moment to pray for them.
4. For those who have elected to have TN surgery, I have great sympathy for those who had invasive surgeries, which seem quite unpleasant. I am not a salesman for *CyberKnife,* and it may not be available in your area, but I would definitely see if it is (link). I feel blessed that while there may only be 6 locations in Illinois with *CyberKnife,* my local hospital (2 miles from my home) was one of those.
5. Official medical literature seems to say that it is unknown why some people get TN. For me, my MRI showed a looped artery that seemed to rub against my nerve, possibly wearing down the nerve sheath. From a purely physical point of view, I assume that is accurate. But it is also known that high stress can cause health issues. Looking back, there were a couple projects that I was working on that were very stressful, and while I would not be able to prove a correlation, I do suspect one.

   From a physiological point of view, I have this hypothesis: during the 2 years that I was under a great deal of stress, I believed I was handling it well at an emotional level. I handled frustration and anger in healthy ways and kept my relationships in good repair. Because I was controlling the stress emotionally, I assumed that it wasn't hurting me physically. But perhaps it was, and I just unaware of it. I will certainly be more cognizant of this in the future.
6. The day I was finally diagnosed with TN and prescribed the right medicine, it was in the "nick of time." The very next day I was scheduled to fly from Chicago to Montana. I was fearful of having an attack on the plane, because I cannot just sit still and quiet during an attack. And 3 days after that, I was looking forward to walking my first daughter "down the aisle"—another time I would not have liked to have had an attack. But the prescription kicked in from the first day and everything went perfectly. Again, I felt blessed to be able to have seen 3 specialists and get my prescription in the 8 days prior to my trip.
7. That I could, within just 11 days, consult with my surgeon, take an MRI and CT, and have my surgery is another amazing blessing that I am very grateful for.
8. My struggles with TN would have been so much worse without the support of my dear wife, many helpful friends, and the *Facial Pain Association* website. I am greatly indebted to them. Above all, I'm grateful for my gracious God who knows, cares, and answers prayers. I've seen too many "coincidences" for me to view them as mere coincidences. When people ask me how I'm *really* doing, my short answer now is: "Only my body hurts. My soul is rejoicing in the goodness of God."
9. If you suffer with TN please don't ever lose hope. I have found peace in the Scriptures such as "We have troubles all around us, but we are not defeated. We often don't know what to do, but we don't give up. We are persecuted, but God does not leave us. We are hurt sometimes, but we are not destroyed." as taken from 2 Corinthians 4:7-5:9. A friend of mine, DeLoris, comforts herself through her bouts of TN with these verses: Isaiah 41:10, Revelation 21:3-4, 1 Peter 5:7, and 2 Corinthians 1: 3-7.
10. Finally, I would not dare to offer advice to other TN sufferers based on my own limited experience, but I would encourage you to do your own research, see your doctors, and keep reaching out to your support network for help. Beyond that, in your most difficult times, if you would like me to pray for you, feel free to email me at 8550@outlook.com. God bless you.