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another perspective™

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IRSA

Trigeminal Neuralgia... The Whole Family Suffers

Alix is the daughter of Richard, who suffers with the pain and effects of trigeminal neuralgia. Her poignant story about her father shows us how the whole family suffers when one member is ill.

For the past three years my father has suffered with trigeminal neuralgia. What I thought was merely stress from work turned out to be something completely different: something which altered my father's "state of being" for a long time. Trigeminal neuralgia (TN) is a painful disorder of the fifth cranial nerve, called the trigeminal nerve. The nerve arises in the brain, supplying movement and feeling in the face. Trigeminal neuralgia affects one in every 25,000 people, making it a fairly rare condition, but common enough so that there are treatments available.

It wasn't until last year that my father was diagnosed with TN, and my family and I finally could put a name to what was causing my father's suffering. Although I didn't know as much as my parents knew, I knew that my father was not the same man that I was used to having around the house. Over a period of about six months, he pulled a Jekyll and Hyde on me, and I realized that I didn't know who he was.

In the beginning, it wasn't bad. My father would come home tired and cranky and go to sleep. On other nights he would sit and watch TV and when my mother called him to dinner he would come, but would only be able to eat a small portion of even the softest food, as the chewing action caused severe pain. He could not even eat ice cream, so he resorted to drinking liquid dietary drinks through a straw, which also caused him a lot of pain. He finally stopped eating to the extent that he lost more than 30 pounds in about two months.

My mom and I used to sit at the dinner table and watch him try to eat. I felt extremely selfish that I had a plateful of food to eat without pain, and he could eat nothing. For months all we had for dinner was soft, non-abrasive food of some sort, because that was all my dad could try to eat.

But it wasn't just eating that was upsetting. As the pain progressed, my father stopped going to work, as talking and writing triggered painful attacks. I used to come home from school and find him asleep upstairs, flat on his back, cringing even in his sleep from the pain. I really didn't understand much of the whole thing, but I tried to be brave.

Alix

So he slept a lot and didn't eat much. That got to be the normal scene in my house, but then the temper came with his pain. I didn't want to go near him, because he was angry at his disease and it seemed that anything I wanted to do or say was upsetting to him because of the pain in his head. While my father was having an attack, he used to draw pictures of demons sitting on a human head, scratching above the eyes with long claws. I guess it was his way of expressing his anger and identifying his pain. He used to say that it was like having a little demon sitting on his head, and every morning when he woke up the demon would be sleeping for a short time, but would wake up quickly enough to remind him that he was still there. My father said the demon used to laugh and mock him. No wonder people with this disease often contemplate suicide!

Finally, he and my mom went to a convention of the Trigeminal Neuralgia Association in Orlando in the fall of 1998. He met others suffering the same type of pain and spoke with several neurosurgeons who described hopeful techniques not to cure his affliction,

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Stereotactic Radiosurgery

Stereotactic radiosurgery is not surgery. The skull is never opened. Radiosurgery involves the use of precisely directed single fractions of radiation to create lesions within the brain or to treat tumors or vascular malformations with minimal damage to surrounding structures or tissues.

This works by delivering a relatively high dose of radiation in one session to the target with scalpel-like precision. The dose is designed to injure or kill the cells or their supporting blood vessels, while minimizing its effect on surrounding healthy tissue. The radiation distorts the cells' DNA, causing them to lose the ability to replicate themselves. The safety and clinical effectiveness of this technique has been established since 1968 in over 150,000 treated individuals.

The benefits include: No risks of infection or anesthesia reactions; virtually no pain; reduced costs; and an immediate return to normal activities.

Radiosurgery may or may not be appropriate for your condition. It may be used as the primary treatment or recommended in addition to other treatments you may need. Only a treating neurosurgeon can make the evaluation as to whether you can be treated. Some of the most common indications for treatment today are:

- Arteriovenous/vascular malformations
- Meningiomas
- Acoustic neuromas
- Pituitary and pineal tumors
- Metastatic tumors
- Glial and astrocytoma tumors
- All other malignant & benign tumors
- Trigeminal neuralgia
- Parkinson's tremors/rigidity
- Functional disorders

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Claire Patterson — The Angel of TN

When this grandmother first began suffering what some call the worst pain on earth, in 1978, she was one of the lucky ones: she was correctly diagnosed with trigeminal neuralgia (TN). Many are told for years that it is a dental problem or some other medical condition. By 1987, medication had proven ineffective and surgery became her only option. After much research, she had the surgical procedure, microvascular decompression. Through all of this, Claire realized there was no where a TN sufferer could turn for help or information. In 1990 she took it upon herself to begin the Trigeminal Neuralgia Association, and to help others obtain the information it was so hard for her to find when she was in pain.

Initially, the Association consisted of Claire's kitchen counter, a wall telephone, and a lot of good intentions. Today, not quite 10 years later, there are nearly 11,000 patients in the Trigeminal Neuralgia Association's database from more than 30 different countries. Claire has built the Association while supporting her daughter through a long illness with breast cancer and eventual death. Since then, she has dedicated herself to her grandchildren as well as the Association.

Claire is well known for her spirit, drive and sense of humor. She has a 'quip' for any situation. One of her favorites is "I choose the hills I am prepared to die for." Claire has dedicated herself to others.

It is because of her effort and determination that we dedicate this issue to a true angel, Claire Patterson, the founder and president of the Trigeminal Neuralgia Association.

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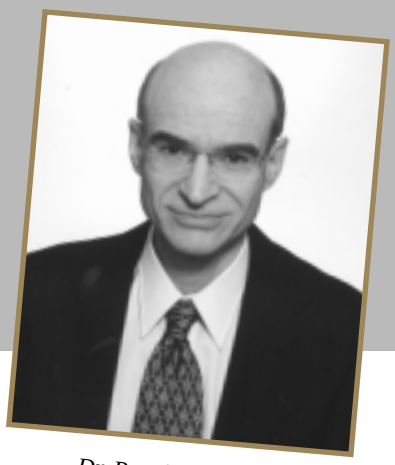
Trigeminal Neuralgia and the Use of Radiosurgery



Dr. Ronald Brisman

Trigeminal neuralgia (TN) is paroxysmal triggered face pain. Most patients respond very well to radiosurgery with the Gamma Knife, which is one of the best standard treatments for this condition.

Symptoms

Trigeminal neuralgia is characterized by sudden bursts (paroxysms) of face pain. These bursts are often triggered by a light touch around the mouth or face or by talking, eating, or brushing one's teeth. The pain sometimes gets worse or better for periods of weeks or months. The pain is in the areas supplied by the trigeminal nerve: the cheeks, jaw, teeth, gums, lips and less often around the eye or forehead. Usually pain occurs on just one side of the face, but in five to 10 percent of patients, pain occurs on both sides of the face, although not at the same time. The pain responds to Tegretol (carbamazepine is the generic name), but sometimes the dose has to be increased and unpleasant side effects can occur.

Atypical features may coexist with some of the previously described symptoms. These atypical features may include a constant pain that is not always triggered by light touch. Patients with constant pain and TN are sometimes diagnosed as having atypical trigeminal neuralgia. Gamma Knife radiosurgery and other treatments for TN usually relieve the sharp electric-like pains that are triggered by light touch, but are less likely to relieve the constant, untriggered pains.

Incidence and Prevalence

Approximately 14,000 people develop TN each year in the United States; about 140,000 people have the condition. Trigeminal neuralgia is more common in patients with multiple sclerosis.

Cause

The cause of trigeminal neuralgia is not always certain. Approximately five percent of patients have a tumor pressing on the trigeminal nerve where it leaves the brain, while other patients have a blood vessel that presses on the trigeminal nerve, close to the brain. In some patients the cause cannot be determined.

Approximately five percent of patients with trigeminal neuralgia have multiple sclerosis. Patients with TN and multiple sclerosis are generally younger, and tend to first experience TN symptoms while in their mid 40s. These patients are more likely to have pain on both sides of the face (bilateral trigeminal neuralgia) and often have other neurological abnormalities, such as weakness or numbness in the arms or legs, dizziness, unsteadiness and double vision. Most patients in their 40s and 50s who have trigeminal neuralgia do not have multiple sclerosis. Patients who have TN but not multiple sclerosis tend to first experience TN symptoms while in their mid 50s.

Diagnosis

In addition to a thorough history and physical examination, magnetic resonance imaging (MRI) of the brain is recommended. This procedure helps identify a brain tumor in the rare cases in which it is present along with TN. It may also help to diagnose multiple sclerosis. Often when the MRI is performed, some contrast material is injected into the vein so that the appearance of a small tumor, blood vessel, or other structures in the brain can be enhanced and made easier to detect.

Nonsurgical Treatment

There are some patients who have very mild face pain that may subside and even disappear without treatment. For severe pain, medications, especially Tegretol, are often highly effective. Tegretol can cause many side effects including sleepiness, forgetfulness, confusion, drowsiness, dizziness and nausea. Tegretol can also cause more serious problems such as bone marrow suppression, which can lead to anemia or a decrease in the number of white blood cells. A low white blood cell count can predispose a patient to contracting an infection. Rarely, these problems are life threatening. Blood counts must be monitored in order to lessen the chance of these complications occurring. Tegretol can also harm many other parts of the body, so patients who take this medicine must be under careful medical supervision. Tegretol interacts with many medications, so patients must advise their doctor of all the medications they are taking. Elderly patients and those with multiple sclerosis are more likely to experience the side effects of Tegretol.

There are other medications that can be used either alone or in combination to control trigeminal neuralgia pain. These are usually less effective than Tegretol. They include Lioresal (baclofen), Dilantin (phenytoin), Klonopin (clonazepam), Neurontin (gabapentin), or Lamictal (lamotrigine). All of them, except baclofen, are also used to prevent seizures.

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Research

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Surgical Treatment

A surgical procedure is recommended for patients who continue to experience severe pain or side effects from medications. In the past, patients with TN did not consider neurosurgical options until the pain or medicines became unbearable, because surgical procedures carried higher risks. Now that surgery is safer, and especially with GKRS, which is not only highly effective but safer than any of the other procedures, patients no longer have to wait to be in agony in order to undergo neurosurgical intervention.

There are five important neurosurgical procedures. Each is effective, but not always, and occasionally has to be repeated. These procedures are: Gamma Knife radiosurgery (GKRS), radiofrequency electrocoagulation (RFE), glycerol injection (GLY), balloon microcompression (BMC), and microvascular decompression (MVD). All of these procedures treat the trigeminal nerve at around the same place, close to where it leaves the brain.

Gamma Knife radiosurgery is the most recent and least invasive neurosurgical treatment for trigeminal neuralgia. Of all the surgical procedures, it is least likely to cause complications and uncomfortable new facial sensations (dysesthesias).

What is Gamma Knife Radiosurgery?

Gamma Knife radiosurgery is a method for treating certain problems in the brain without making an incision. Two hundred-one beams of cobalt^{60} radiation are focused precisely on a specific region in the brain. In the case of TN, the target area is the trigeminal nerve, just where it leaves the brain. The treatment does not require general anesthesia, and the patient stays in the hospital for less than five hours.

Who is a candidate for Gamma Knife Radiosurgery?

Any patient with trigeminal neuralgia who has pain or has difficulty with the medicines used to relieve the pain is an excellent candidate for GKRS. The patient's age or medical condition does not affect the decision to have GKRS. Even the elderly or medically infirm can undergo this treatment. Patients who are receiving anticoagulants for other medical conditions do not have to stop or reverse the anticoagulation therapy prior to GKRS. Those who have had previous procedures for TN may also undergo GKRS. Patients who are concerned about the possibility of numbness are particularly good candidates for GKRS, because the chance of postoperative numbness occurring is very small. Patients who poorly tolerate medicines given for sedation and relief of pain during a procedure are also very suitable for GKRS because these medications are not necessary.

What results can be expected from GKRS?

Excellent or good pain relief occurs in approximately 85 to 90 percent of patients. Onset of pain relief may occur one day to four months after the procedure. About half of patients will experience pain relief within four weeks. Recurrent pain occurs within three years in 10 percent of patients. Patients with TN and multiple sclerosis are less likely to respond to GKRS than those without multiple sclerosis, although they also may be helped by the procedure. Gamma Knife radiosurgery can be repeated, but not until at least four months after the original procedure.

FAST FACTS

- TN is rarely (4%) suffered in the Upper Branch
- Right side is more frequently affected than left
- A small percentage suffer pain in both sides of the face
- Most common in the Middle and Lower Branches
- 15,000 new cases annually in USA
- 1 in 2,500 suffer TN
- More frequent in women
- Most people over 40 years old
- Estimated 5% family history

What are the complications from GKRS?

Major complications have not been reported. Additional numbness in the face or new facial sensations occur in less than 10 percent of patients. There are theoretical possibilities of delayed complications such as brain damage or brain tumor formation, but these are rare and have not been reported to occur in any patients treated for trigeminal neuralgia.

Gamma Knife radiosurgery was first performed in Sweden in the 1950s, but few patients were treated for TN. The Gamma Knife has been used in the United States since 1987, and most cases of TN have been treated during the past five years. Although there is not much information on long term effects, initial and medium range follow-up suggest that GKRS is not only effective but also very safe.

Linear Accelerator Radiosurgery

There is another form of radiosurgery, called LINAC (Linear Accelerator) radiosurgery. It uses high-energy X-rays delivered by a sequence of arcs, and is very different from GKRS. Only a few cases of TN have been treated with LINAC radiosurgery, and there are no reports on these cases in peer-reviewed journals. Unlike GKRS, LINAC radiosurgery has not been demonstrated to be an effective and safe treatment for trigeminal neuralgia.

Radiofrequency Electrocoagulation, Glycerol Injection and Balloon Microcompression

These procedures are performed through a needle that is inserted into the face and directed, under X-ray guidance, toward the trigeminal nerve. All of these procedures partially damage the nerve and often cause facial numbness, which is sometimes very painful. Major complications, such as bleeding or infection in the brain, are rare but can be devastating when they occur.

Microvascular Decompression

Microvascular decompression is a major neurosurgical procedure in which the skull is opened. During the operation, which requires general anesthesia, the surgeon sees the nerve. If he or she finds a blood vessel pressing on the trigeminal nerve, a soft piece of material will be placed between the blood vessel and the nerve, thus lifting the blood vessel away from the nerve. This operation carries greater risks than the other procedures do, and these risks, although infrequent, include possible death, stroke, bleeding, infection, inflammation of the

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National Brain Tumor Foundation Conference
March 31-April 2, 2000
Los Angeles Airport Hilton Hotel
Los Angeles, CA, USA
+800-934-CURE (2873)
www.braintumor.org

The Brain Tumor Society Frontiers of Hope Symposium
November 12-14, 1999
Rhode Island Convention Center
Providence, RI, USA
+800-770-8287
www.tbts.org

Trigeminal Neuralgia Association Third National Conference
October 26-29, 2000
Pittsburgh, PA, USA
+904-797-0333
www.tna-support.org

Commentary : Trigeminal Neuralgia and the Use of Radiosurgery

Trigeminal neuralgia (TN) is a pain for patients but a joy for neurosurgeons! One cause for joy is the fact that TN is easily diagnosed: it consists of electrical shock-like pains in one or both sides of the face, and usually responds to carbamazepine (Tegretol), an anti-seizure medication. A second reason is that every treatment the surgeon performs is usually very effective. Many are simple outpatient procedures.

Patients should consider effectiveness, cost, recurrence rate and complications when choosing their surgical approach. In general, the more effective measures last longer but have a greater chance of inducing permanent numbness in the face. For example, radio-frequency electrocoagulation is more than 95% effective in initial pain control and has low pain recurrence rates, but many individuals will have permanent numbness in the face. Conversely, glycerol injection into the nerve yields a lower chance of pain relief (80 to 85%), and does not usually cause permanent numbness, but pain frequently recurs within a few years.

Dr. Brisman has nicely outlined the pathology, diagnosis and various surgical treatments for TN. I have treated approximately 80 TN patients at the San Diego Gamma Knife Center. In a survey of our patients with typical TN, 86% achieved good to excellent pain relief. No facial numbness occurred in our cases but 1/3 of patients reported transient tingling in the face. Increasing radiation doses during treatment are now under study.

Finally, I want to reemphasize a point made by Dr. Brisman in his article. Gamma Knife radiosurgery (the only radiosurgery instrument with significant positive peer-reviewed research) approaches the effectiveness of all other surgical treatments and is extremely safe and convenient. It should be considered as an alternative to effective medical management rather than a last resort once the medicine fails. More information on TN can be found in our web site: www.sd-neurosurgeon.com.

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Research

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surface of the brain, facial weakness, hearing loss, facial numbness and pain.

Summary

Gamma Knife radiosurgery is a major advance in the treatment of trigeminal neuralgia, an otherwise agonizing condition characterized by paroxysmal triggered face pain. Gamma Knife radiosurgery not only relieves the pain as well as the other neurosurgical forms of treatment, but it does so with fewer complications.

The Gamma Knife is the only radiosurgical machine for which positive results of trigeminal neuralgia treatment have been published in peer-reviewed journals.

Dr. Brisman is a graduate of Harvard Medical School and served as Chief of Neurosurgery US Army 24th Evacuation Hospital in Vietnam. He has performed more than 1400 surgical procedures on TN patients and more than 125 radiosurgical procedures. He serves on the Medical Advisory Board to the Trigeminal Neuralgia Association. He may be reached at Columbia Presbyterian Medical Center in New York City at +212-305-5285 or by e-mail at: rb36@columbia.edu.

High Blood Pressure First Sign of Malignant Tumor

Randy was diagnosed with debilitating high blood pressure in 1997 at the age of 33. He had been having blackout spells and severe headaches, which were attributed to his high blood pressure. Randy also experienced numbness which progressed to stumbling. "There were episodes where he would fall to his knees and see darkness, and voices sounded far away," his wife Tammy recalls.

With these problems Randy had been unable to work full time. He was scheduled for an MRI in October of 1998 but canceled because the family did not have health insurance provided by their employers. The MRI would cost $1500. The receptionist from the MRI office called and convinced him to have the MRI anyway. The MRI showed a brain tumor "shaped like a marble with butterfly wings" in the center of Randy's brain. He was diagnosed with a malignant anaplastic ependymoma in the third ventricle of the brain. The tumor had caused a buildup of cerebrospinal fluid in the ventricles. This buildup was the cause of Randy's high blood pressure.

In November of 1998, Dr. Geofrey Blatt performed a craniotomy and removed a large amount of the tumor. The surgeon also created a new route for the spinal fluid to drain from the ventricles. Surgery was performed at Kansas City Research Hospital in Missouri. After the surgery, Randy no longer had high blood pressure.

Later that same month, Dr. Blatt performed Gamma Knife radiosurgery on the remaining part of the tumor in Randy's brain. Randy then had six weeks of radiation therapy around the tumor area to eliminate any stray malignant cells. His tumor has not been visible on subsequent MRIs.

"The community has really rallied around us," Tammy says. "On the day of Randy's Gamma Knife treatment, a nurse told us that the hospital had adopted us as their 'Christmas family.' They bought gifts for the kids." The community held a ham and bean supper fundraiser and raised money to assist with Randy's medical bills.

This past summer Randy and Tammy took a trip to the Colorado mountains with her parents. "He got really sick going up in the mountains two years ago. He said he felt like his head would blow off [because of his high blood pressure]. But he didn't feel like that this time," Tammy says.

The Carrolls have coped with their large medical bills by selling their tractor, truck, and one of Tammy's beloved horses. "It has been really hard on the family," Tammy says. "Our strong faith in God helps a lot." Tammy lost her job during this period, but she has continued to strive to finish a degree in teaching. Recently, she organized a fund-raiser which raised $1000 for the American Brain Tumor Association.

Randy deals with aphasia in which "I have trouble finding the right words sometimes. I get mixed up," he says. He enjoys working in the family's garden in Deepwater, Missouri. Randy and Tammy are blessed with three children: Joel, 16, Rachel, 14 and Elizabeth, nine.

Current Research...

The region of human DNA involved in determining sensitivity to pain has been identified.

Investigators at the U.S. National Institutes of Health in Baltimore, Maryland have reviewed studies on the genes responsible for the density of "mu" opiate receptors. These receptors are specialized proteins that bind with the body's natural opiates to help reduce pain.

Results of the review showed that mice with no or few mu opiate receptors have lower overall pain thresholds. These animals also require greater amounts of morphine to dull pain, compared to control animals.

In addition, the entire human genomic DNA region that encodes mu receptors has been identified. Research to locate the specific genes responsible for human opiate receptor density is being conducted.

-- from the journal Proceedings of the National Academy of Sciences 1999;96(14): 7752-7755.

Promising results have been reported from a trial of an experimental brain tumor therapy in which microscopic implants deliver chemotherapy agents directly to the brain.

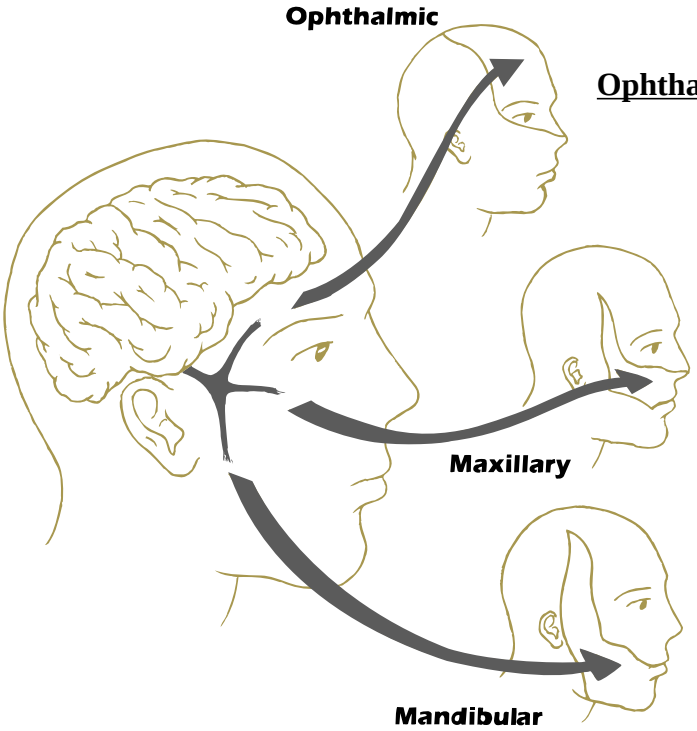
Researchers at the Centre Hospitalo-Universitaire d'Angers in Angers Cedex, France, treated eight adults with glioblastomas using microscopic beads embedded with small amounts of the anticancer drug 5-fluorouracil. After surgical removal of the glioblastomas, the microspheres were inserted around the cancer site. All patients underwent radiation therapy in addition to the microsphere treatment.

The researchers found that patients' median survival time was 98 weeks, which is nearly double the average one-year survival associated with traditional therapy. The authors noted that the microsphere treatment was well tolerated by most patients and that the spheres degraded harmlessly within about two months of implantation.

-- from the journal Cancer 1999; 86(2):197-199

Know Your Nerve

Trigeminal neuralgia is a disorder of the 5th cranial nerve. This nerve is the largest of the 12 pairs of cranial nerves. There are three branches to the trigeminal nerve: the Ophthalmic Branch, the Maxillary, and the Mandibular Branches. A brief listing of what is affected by each Branch follows.



Ophthalmic: Forehead, frontal portion of scalp, eye, eyebrow. (Also known as the Upper or 1st Branch.)

Maxillary: Cheek, lower eyelid, side of nose, upper lip, upper teeth and upper gum. (Also known as the Middle or 2nd Branch).

Mandibular: Side of tongue, lower lip, lower teeth, lower gum, and a narrow strip that extends from in front of the ear along the lower jaw to the side of the head. (Also known as the Lower or 3rd Branch.)

History of Trigeminal Neuralgia

Greek and Roman physicians first recognized trigeminal neuralgia, with descriptions of the pain in the writings of Aretaeus (in The Cappadocian) as far back as the 1st century AD. The anguish of the condition is portrayed in Wells Cathedral in Somerset, England, by 16th century carvings showing contorted facial expressions of agony on the sufferers. Early treatments dating back to the 17th century included phlebotomy (bloodletting) and preparations that used caustic chemical dressings, and poisons such as arsenic, mercury, hemlock, and cobra and bee venom. In 1677 an American physician and philosopher, John Locke, described the condition occurring in the wife of an English ambassador, the Countess of Northumberland. Distinguished physicians such as Fothergill and Pujol wrote detailed clinical accounts in the late 1700s. The recognition of trigeminal neuralgia as a definite clinical entity remains credited to the French surgeon, Nicolaus André. In 1756, he published a comprehensive description of the condition from several cases he had encountered, giving it the name, tic douloureux - literally "painful spasm."

In the 1930s, a pioneering American neurosurgeon, Walter Dandy, noted the frequent occurrence of a blood vessel in close proximity to the point where the trigeminal nerve enters the brain. It was not until the 1960s - when the operating microscope became a standard tool in the neurosurgical operating room - that the neurosurgeon Peter Jannetta popularized the idea that a blood vessel compressing the trigeminal nerve may be the cause of pain.

Reprinted with permission from the Neural Network, Fall 1998, University of Maryland Department of Neurosurgery

The Battle with TN Continues for Some

I was stirring spaghetti sauce at the stove, and telling my son David a funny joke, when I got what felt like a flash of electric current in my left eye. The pain was so severe that I was stunned for a moment. This happened again a couple of days later. I was in the shower and had put my face up to the spray, and the pain sent me to the other end of the tub, shaking and scared out of my wits. That shot of pain felt like it had gone from my eye clear to the back of my head.

This happened occasionally for about a month, and I finally had to give up and see the doctor. He sent me to have an eye exam, not to see an ophthalmologist, and I was told that I just needed glasses. So that was that. The day I picked up my glasses I had no more pain. "Whoopee! Simple!" I thought.

During the summer of 1991 we sold our house. Our son had graduated, married and had two children, and we thought the entire family would have a lot of fun swimming and boating. We bought two acres at the edge of a beautiful lake. On the property was an old house with a caved-in roof. It was full of dead cats and slimy snail trails, and it smelled so horrible that you couldn't get near the boarded up windows.

We had a lot of rain that winter but worked through it with the help of two hired helpers and various good friends. We tore down the old house and framed the new one. We were living in a 35-foot travel trailer with a huge, four cans of Alpo at each meal, part-Newfoundland dog, which was too wide to step over and too long to walk around. There were four baby kittens which climbed on me, clear to my shoulders every time my hands were in the sink. We also had grandkids a lot of the time. With all this, I never lost my mind once.

In early November 1995, the new house wasn't quite completed. We were still working on the interior when the eye shocks returned. They were in my left eye and were much worse than before. They lasted longer and were minutes apart. The worst attacks were in the early morning. I put off going to have my eyes checked because we didn't have insurance that covered new glasses, but the pain became so terrible that I had to see our family doctor.

My face got very cold in the car on the way to the appointment and I had two terrible pain attacks in his office. He told me he suspected glaucoma and that he'd set up an appointment with an ophthalmologist the following morning. However, I saw the letter he sent to the

Donna

specialist and he had written, "suspected trigeminal neuralgia." The ophthalmologist told me I almost certainly have trigeminal neuralgia (TN) and made an appointment for early the next morning with a neurologist. The neurologist confirmed that I have trigeminal neuralgia.

I had never heard of this disorder and asked a lot of questions that were not answered. When I asked where the trigeminal nerves are, the neurologist just indicated the side of his head, and didn't explain anything more.

I asked if there were any medications that would help and he said, "aspirin is as good as it gets," so I thought, "Oh, goody, a piece of cake to control."

I asked if surgery might take care of the disorder and he mentioned "RF [percutaneous radiofrequency]" and "MVD [microvascular decompression]," and did not explain what they meant.

I asked if there are others with TN that I could talk with. The doctor said that he saw only one or two cases of TN, every now and then.

I asked if there was any literature I could read that would explain TN, and he told me that not much has been written about TN. That was the end of the visit, after he gave me a prescription for Tegretol.

When I picked up the prescription I asked the pharmacist what side effects there might be, and I was told only that the Tegretol might make me a little drowsy. I started taking the Tegretol and sat in a recliner feeling as if my arms and legs were about to fall off. I couldn't walk straight so I sat for one whole day. That sensation was a little better the following day, but three days later I was sitting on the sofa, folded over a pillow, nauseated and having terrible stomach pains. I felt like that for the next few days. My husband Howard called the neurologist's office. He was on vacation, but his partner was there and he said, very fast, "Tell her to stop taking the Tegretol immediately and go get a baclofen prescription filled."

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Jerome

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but help it. One doctor, Dr. Ronald Brisman of the Columbia Presbyterian Hospital in New York City told him about the Gamma Knife procedure and of the possibilities for success with that. He made the decision to try that, and headed for New York on the day before Thanksgiving. In this procedure, the nerve is dulled or killed by a concentration of cobalt beams.

When my father came home there was much reason for optimism. The pains began to disappear and gradually during December they left him and he got progressively more like his old self. His feeling better for Christmas was the best thing that I could ever have asked for. I was so relieved and happy that I considered it a "Christmas miracle."

Battle

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It turned out that the Tegretol was goofing up my liver, but neither the Tegretol nor baclofen helped the pain. Suddenly, I couldn't touch anywhere near my nose or eye. I started getting shocks in my lips and the roof of my mouth, and then it began in my right eye. The pain was so bad that I just sat on the sofa waiting for the next shocks to strike, and they did, minutes apart. I know we're not supposed to get pain while we sleep but I did.

The neurologist's nurse told me she had seen a story in a nursing magazine about the Trigeminal Neuralgia Association. I stopped sending Howard on useless trips to the library, looking for anything on TN, and called Claire Patterson. She was wonderful. She called and sent me a back issue of the Trigeminal Neuralgia Association's newsletter that described various surgeries, far more than my neurologist had mentioned.

I started doing my homework and sent a letter to Dr. Ronald Young in Seattle. He called and was kind and informative, and answered every question I had. Because my optic nerve was involved, I couldn't afford to risk any procedures that could cause corneal damage. I believe I made the right choice to have Gamma Knife radiosurgery.

Soon after this, a nurse called and told me, "Dr. Young would like to see you, and we'll take care of all the paperwork." We left for the 350-mile drive to Seattle, to my sister's home, early the next morning. I called Dr. Young's office and was given an appointment for a few days later. A few days after that, on February 19, 1996, I had Gamma Knife radiosurgery at Northwest Hospital in Seattle, Washington. Afterwards, I stayed in touch with the International Radiosurgery Support Association and Becky Emerick, who helped me over some very rough times.

I wish I had been one of the lucky patients who have really fast relief. But just before radiosurgery I had really long shocks in my left eye, and short, bad ones in my nose, lips, and the roof of my mouth. When I came out of the Gamma Knife unit, the really long shocks in my eye never happened again, but I still had the frequent, short shocks there, and nothing had changed anywhere else.

I went through a period of terrible fear that the radiosurgery had failed. Everything I had read indicated it should have already worked. I was really frantic, and the pain escalated, probably in large part due to the fear. I was taking huge amounts of Neurontin and that, combined with the fear, interfered with normal thinking and reasoning. I couldn't believe that what I had read, written by neurosurgeons, could be wrong. I thought the radiosurgery should have already stopped my pain. I was told that it takes time to work.

Four months to the day after radiosurgery, I could touch the side and tip of my nose fairly often. Everything else stayed the same for another six months or so, but there were changes along the way. The pains became less intense and less frequent. And, during that time the pain actually got worse for a while before it started getting easier. I think it was November 18, 1998 that I took my last pills. I still had flickers of pain but nothing I couldn't deal with. The best part is, I have no numbness. My right side is in remission, and I'll have radiosurgery on it if it comes out of remission, but without all the fear I had three years ago.

Recently, I have had some return of pain and I am considering retreatment where a different dosage or target site can be done. Radiosurgery is still the treatment for me. It is my understanding that since I was one of the early patients treated, I was given a lower dosage than is commonly given now.

I wish everyone could know that it can take awhile for radiosurgery to stop the pain. I know of one patient who thought her radiosurgery had failed, and she had a RF procedure and a nerve block after the RF, all within five months. Radiosurgery does not work instantly, but the wait is worth it because it doesn't leave patients with the bad side effects that other procedures do.

Letters, calls, and e-mails are welcome from any radiosurgery patients or anyone who is interested in Gamma Knife radiosurgery. And, anyone in the Tucson area, please call me. I promise very good apple pie if anyone can get together.

COMMON TN TRIGGERS

- A light breeze
- Cold
- Vibrations
- Brushing Teeth
- Shaving
- Eating
- Talking

Protect Yourself from Health Fraud

Unproven medical treatments can waste your money and endanger your health. Many of these fraudulent claims are made regarding treatments for serious health problems such as tumors, cancer and pain. Be careful if:

- the product is only available from one source
- payment is requested in advance
- the product claims to quickly cure multiple diseases
- the label or advertisement states "secret ingredient,"
- "scientific breakthrough" or "amazing results"
- advertisements include anonymous testimonials

Extensive Dental Work Did Not Help Pain of TN

Edmund and Becky

"It was a hot poker-like pain that started in the base of my right nostril," Becky says of the pain caused by trigeminal neuralgia. While she was in her early 30s, she tended to have pain several times daily when eating and talking.

Her dentist removed all the fillings in her upper right teeth, but the pain continued to increase in intensity. At this time Becky was a single parent, working full-time while finishing her Bachelor of Science in nursing.

Six months to a year after the first symptoms, the pain started occurring when she was talking. "By this time I was eating only pureed foods," Becky says. "An oral surgeon took out my wisdom tooth on the right side, but the pain got worse!" she recalls.

While working as an ICU nurse, a neurosurgeon that Becky worked with suggested that she come to see him. He diagnosed her with trigeminal neuralgia (TN). "I'd never heard much about TN, even though I was a nurse in an ICU," Becky says. To control her pain, she took increasing doses of Tegretol for three years. "The Tegretol made it hard for me to concentrate," Becky says. "I told my employees and co-workers to keep an eye on me and make sure I was making rational decisions." After a few years the Tegretol had less and less effect, and the pain seemed worse than it did originally.

In December of 1986, Becky had a surgically invasive procedure called a microvascular decompression. Although she developed a form of meningitis (an inflammation of the brain lining) over the Christmas holidays, she "had no pain attacks and was 100% medication- and pain-free until 1991."

In 1991, the pain returned while she was eating. "The pain began at the tip of my tongue and traveled down the right side of my tongue, then radiated to my ear, then came down my jaw to my chin. The whole circuit would remain painful for about a minute," Becky recalls. She likens the pain to labor contractions, which return on a regular basis. "The attacks were more frequent and lasted longer than before. I couldn't eat anything," she says.

> **As a general rule, the most successful man in life is the man who has the best information.**
>
> BENJAMIN DISRAELI

Becky returned to her surgeon, who recommended percutaneous radiofrequency. Dr. Ronald Brisman at Columbia Presbyterian Hospital in New York City offered her a second opinion, again suggesting percutaneous radiofrequency. He performed the procedure in November of 1991. "After that, it took me a few weeks to figure out how to talk," Becky recalls. "But then I was pain-free until March of 1998."

In March of 1998, Becky needed a root canal on a molar on the lower right side. "Within 24 hours of the procedure being completed, the pain returned," Becky recalls. She went back on Tegretol, taking increasing doses, up to 1200 mg/day. "It was debilitating. I couldn't function or drive," she says.

She returned to Dr. Brisman and he performed Gamma Knife radiosurgery on her in June of 1998. "I didn't drive until September. My daughter drove," Becky says. She has been pain- and medication-free since September 1998.

"There are some words I can't say, and some food that I can't taste," she says. "My tongue feels like it's not always mine, but it's worse when I'm tired." As a result of her invasive procedures, she also has a greater tendency to choke.

"With each treatment, I believed the pain was gone forever," Becky says. And with each outbreak, she felt more despair. "I withdrew socially, because social activities such as talking and eating caused pain," she recalls. However, Becky is "not terrified that the TN will come back, because there are new and better treatment modalities all the time."

Becky recommends Gamma Knife radiosurgery and would repeat it. "It's not as frightening and is less debilitating than other procedures," she notes. "It also requires less recovery time."

While on a cruise around the coast of Maine this past August, Becky married her husband, Edmund. They were married on an uninhabited island overlooking Penobscot Bay. Becky also completed her nurse practitioners' requirements in August and will be taking her certification exams in September. Becky is 47 and has a daughter, Melinda, 26, and a son, David, 28. Becky and Edmund love cats and have a multitude of indoor and outdoor cats.

Ensure Your Decisions Are Known

Advance directives express your wishes regarding your health care or finances in a legally binding document. They go into effect in the event that you become unable to make your own health care decisions. Both living wills and health care powers of attorney are advance directives. An advance health care directive merges aspects of a living will and a health care power of attorney.

A living will, also known as a healthcare directive, states what type of treatment you want to receive. Commonly, a living will communicates your wishes concerning life-sustaining procedures. These may include withholding life prolonging treatments in the event of a terminal illness, or reinforcing that you would like to receive all medical treatment that is available.

Once your doctor receives a valid (signed and witnessed) directive, he or she is obligated to either honor your wishes or transfer you to the care of another doctor who will. A living will goes into effect when you are unable to make your own decisions regarding your healthcare.

A power of attorney gives your legal rights to another person, allowing him or her to pay your bills and handle your affairs until you are able to manage them. A healthcare power of attorney gives the person ("agent") you specify the authority to make medical decisions on your behalf, in the event you are unable to do so. Realize that your agent may have to confront your physicians or family to ensure that your wishes are honored. This directive can be used in both permanent and temporary situations. A healthcare power of attorney becomes effective only when you do not have the capacity to give, withdraw or withhold informed consent regarding your health care. Otherwise, you may continue to make your own decisions regarding your healthcare. You should express your wishes regarding your health care to your agent.

If you do not have an advance directive regarding your healthcare preferences, your physicians will use their discretion in deciding what kind of medical care you will receive. Consent to perform surgery or another major procedure will be obtained from a relative such as a spouse, parent or adult child. Partners and friends are rarely consulted. Give copies of your advance directives to several people, to ensure that they will be followed in the event of an unplanned need for care.

States recognize different types of advance directives. Be sure to contact an attorney who is familiar with your state's laws regarding advance directives.

HEALTH CARE CHOICES SHOULD:

- Fit your needs
- Fit your lifestyle
- Be acceptable to your family
- Be research based
- Be a quality of life decision
- Be your choice

another perspective

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The International Radiosurgery Support Association is an independent organization dedicated to providing information through personal contact and educational materials, encouraging research and promoting patient options about radiosurgery treatment and its availability.

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Benefits of Radiosurgery

- Virtually painless, as it is noninvasive
- No risks of infection, or reaction to anesthesia
- Only abnormal tissue is affected – the surrounding tissue is spared
- A same-day procedure or overnight stay in most cases
- No hair loss or scarring
- Significantly reduced cost compared to microsurgery
- Post-surgical disability is minimal, with return to work usually immediate

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