

Canada TNA News

February/March 2008

Canada TNA

Canada TNA (CaTNA) is a network of support groups and individuals who are dedicated towards sharing information and support to people who have Trigeminal Neuralgia and other facial pain. Membership in CaTNA is \$10 per year. Newsletters are available free by e-mail, and for \$6 per year by Canada Post. Contact: Canada TNA, c/o Jan Williams; 15 Everstone Dr. SW, Suite 207; Calgary, AB, T2Y 5B5. Email: calgary@catna.ca; Phone: (403) 295-0987. Canada TNA is associated with the TNA Association in the USA.

Greetings to all! I hope you are pain free and keeping warm.

There is some exciting news with **Canada TNA** this month. We have two new support group locations in Ontario: Peterborough and Niagara Falls/St. Catherines areas. We owe a big thank you to Marilyn Martin and Brenda Sharp who are going to organize the meetings and look after the groups. Look for some details later in this newsletter.

We are also looking forward to the first meetings of the Winnipeg group this winter. Thank you Marion!

If you do not have a group in your area and are willing to help start one, please contact me and I'll help you get started. You can start small and let the group develop into whatever is best suited to your community and the people who live there.

Jan

Disclaimer: The information in this newsletter is not intended to diagnose or offer advice on treatment of TN. Its sole purpose is to provide information so that you, working with your doctor, can make informed decisions on your own care.

TN Stories:

Brenda – group leader for Niagara Falls Area

I am married with 6 children (blended family). My husband and I work together for a Heavy Civil Construction Company. We travel all over Ontario - building bridges. He is a Project Manager, and I am a Project Administrator. We make a great team!

My TN story began in the 1980's when I was still in my late twenties. After trips to the dentist, and an unnecessary sinus surgery, I was diagnosed with Trigeminal Neuralgia, and started on the medication path with Tegretol. Glycerol injections followed. Just when I thought I couldn't go on anymore, I had a MVD in Toronto. Although relief wasn't immediate, I eventually became pain free. Daily application of Zostrix helped along the way.

After almost 15 years of pain free life, I started feeling those familiar twinges on the opposite side of my face. I worried that I was one of the unlucky ones to have bilateral TN, but I have been okay for several months now. If or when it returns, I will be ready for it this time!

Twenty years ago I felt so alone when I was diagnosed. Now, because of TNA and CaTNA, we have a wonderful support system in place, and I look forward to being part of a local support group in the Niagara Region.

Marilyn – Group Leader for Peterborough

I have had TN since 1990. Like so many other people I tried drugs, naturopathic treatments, and acupuncture all with limited results. After about 5 years I had a radiofrequency Rhizotomy done and that gave me 5 years of pain relief. When the TN came back I had a second Radiofrequency Rhizotomy in 2003. Now although my face is numb, I only have small twinges of pain from time to time. The big TN attacks are gone!

Back in 1990 when I first found out I had TN I would have loved to have found even one other person to talk to because it such a scary thing otherwise that is for sure I am really looking forward to meeting and talking to others in this area.

I am a retired lady living with Monty the wonder dog!

Update: Dee from the Saskatoon Group had an MVD in November. She is now pain free and medication free and back to work looking after her family, her business and the folks in Saskatchewan with TN. Congratulations Dee.

Support Group News

Everyone is welcome to attend a support group meeting. You do not need to be a member of CaTNA although we will be happy to have you join us.

Alberta

Calgary:

The Calgary Support group meets once a month at the Real Canadian Superstore Community Room in Deerfoot Meadows. Contact Jan for information 295-0987 or calgary@catna.ca. The next meetings will be:

Thursday, Feb 21/08, 1:30 pm

Video: MVD by Dr. G Golfinos

Thurs March 20 – 13: pm

Video: Balloon Compression by Dr. Jeffrey Brown

Manitoba

Winnipeg:

Contact Marion at (204) 697-9459 or Winnipeg@catna.ca for dates and locations of the meetings

Ontario

Newmarket

Contact Kathy (905) 853-9849 or Sandra (905)284-9215 or email Toronto@catna.ca for locations and dates.

Niagara Falls and Area

The first meeting for this group will be Feb 23. Contact Brenda at Niagara@catna.ca or (905) 937-6178 for location and time.

Peterborough

Contact Marilyn at (705) 742-1486 or peterborough@catna.ca for meeting times and locations.

Toronto (Thornhill)

The group meets the last Sunday of each month at the Thornhill Community Centre, 7755 Bayview Ave at 9:30 am. Contact Kathy (905) 853-9849 or Sandra (905)284-9215 or by e-mail Toronto@catna.ca The next meetings are: Feb 24th and Mar 30th.

All are welcome; please bring a support person with you. If you would like to meet with Sandra or Kathy at a different time please let us know and we can make some other arrangement. If you live in York Region you can contact Kathy to arrange a meeting there.

West Toronto

Contact Valerie at (416) 588-4951 or westto@catna.ca for dates and locations

Saskatchewan

Saskatoon

Contact Dee at (306) 382-5666 or by e-mail at saskatoon@catna.ca for dates and locations.

Regina

Contact Faye (306) 751-0761 or by e-mail at regina@catna.ca . The next meeting will be Saturday, February 23.

Surgical Management of TN

The following are part of the course notes prepared by Dr. Kaufman and reprinted with permission on the Surgical Management of Trigeminal Neuralgia. These notes were used for a course presented at the Canadian Congress of Neurological Sciences (CCNS), June 2006. The complete notes are available at http://www.umanitoba.ca/cranial_nerves/ccndhome.htm. Reprinted with permission (Continued from the last newsletter)

Emergency Medical Treatment

Emergency treatment of trigeminal neuralgia deserves special mention. Severe exacerbations may not permit the patient opportunity to sufficiently increase their medication intake to control the pain. Emergency room administration of intravenous phenytoin can be very effective, followed by a maintenance dose. Many emergency room patients with trigeminal neuralgia are often given opiate analgesics, which typically are not effective in reducing trigeminal neuralgia pain and should not be prescribed for outpatient trigeminal neuralgia treatment. If emergency room interventions are ineffective, hospital administration for additional intravenous medications such as the combination of lidocaine, ketamine and fentanyl is warranted. Local anesthetic blocks can be administered to buy time, but temptations to perform peripheral ablative procedures (e.g. alcohol injection) should be avoided, and more definitive treatment measures pursued. We perform a few emergency percutaneous rhizotomies and emergency microvascular decompression surgeries each year, with most gratifying results.

Microvascular Decompression

Most patients with typical trigeminal neuralgia who become dissatisfied with medical treatment are candidates for microvascular decompression surgery; if they can withstand the pain attacks, they can probably get through surgery. The surgery is well tolerated by the elderly, although frail individuals or those with significant medical co-morbidities are directed to destructive procedures under local anesthetic as described in the following sections. MVD surgery offers the advantages of attacking the presumed etiology, preserving the trigeminal nerve function, and providing the best chance for permanent pain relief. This surgery is performed through a small thumbprint-sized craniectomy behind the

ipsilateral ear. Microsurgical techniques are employed to mobilize the offending vessels off the symptomatic nerve and maintain their new position with placement of small permanent implants, such as shredded Teflon felt. Initial pain control following surgery is achieved in over 90% of patients, with large series reporting 70% "cure" rates at 10-year follow-up. Success and complication rates are closely related to surgical experience and expertise. Major morbidity and death risk should be less than 0.5% and risk of hearing loss less than 1%. Intraoperative monitoring of auditory evoked potentials should be routinely employed. Permanent trigeminal numbness is also rare, and deafferentation pain including anaesthesia dolorosa is virtually never encountered. Failures and significant recurrence are seen in 10% to 20% of patients, often in association with severe or long-standing vascular compression, previous destructive procedures, and isolated venous neurovascular compression identified at surgery. MVD surgery aims to achieve atraumatic alleviation of the causative pathology (i.e. pulsatile neurovascular compression) resulting in reversal/correction of the neural-pain generating pathophysiology (i.e. trigeminal nucleus hyperactivity). In series by experienced neurosurgeons, the neurovascular compression is universally present and outcomes with microvascular decompression surgery are significantly superior to other trigeminal neuralgia surgeries including the incidence of "life-alternating complications". On the other hand, results of microvascular decompression surgery have the greatest inter-surgeon variability of all trigeminal neuralgia procedures. A recent review of microvascular decompression in the USA indicated that approximately 1,500 operations are performed annually, 1300 for trigeminal neuralgia. More than half the neurosurgeons did only 1 to 3 operations per year and approximately one dozen did more than 30 procedures per year. Although overall morbidity/ mortality rates were extremely small, a significant difference between high and low volume centers and surgeons was demonstrated. Other reports have also pointed out that outcomes and complication rates are closely related to surgeon experience and expertise. Similarly, failure to identify culprit neurovascular compression in patients with

typical trigeminal neuralgia should be considered a failure of surgical technique and is associated with suboptimal outcome results. We have seen many examples of "failed" microvascular decompression where the culprit neurovascular compression was readily apparent and correctible at re-do surgery.

In my own series of over 400 microvascular decompressions performed over the last ten years, there have been no deaths or permanent major morbidities. One patient suffered a postoperative cerebellar venous infarct requiring surgical decompression but without permanent sequelae. One patient had intraoperative venous bleeding from a bridging vein that interrupted surgery; the MVD was successfully completed a few weeks later without difficulty. The incidence of hearing loss has been less than 1% and the postoperative rates of cerebrospinal fluid leak, infection or aseptic meningitis have been 1%, 1% and 3% respectively. Over 90% of patients experienced immediate trigeminal pain relief that has continued without need for medications in over 70% to date. The 2-hour operation is followed by an average length of hospitalization less than 3 days. The patients are not restricted in their activity following surgery and those living far away are flying back home within one week of surgery. The convalescence time ranges between two weeks and two months.

Controlled Destructive Procedures

The surgeon to Louis XIV, Maréchal, pioneered the surgical treatment for facial pain by making a wide intraoral incision to section the infraorbital nerve. In 1756, André reported superior results by destroying the nerve with caustics. Neurectomies were introduced in the 1800s, although surgical and percutaneous rhizotomies of the ganglion and trigeminal root were subsequently found to provide more long-lasting relief and preservation of some facial sensation. The most widely employed "ablative" techniques today include the percutaneous needle approaches to the gasserian ganglion and stereotactic radiosurgery.

These minor procedures avoid the risks of craniotomy, have low morbidity, and nearly no mortality risk. However, patients often experience facial numbness postoperatively, and are at risk to develop corneal anesthesia and keratitis, trigeminal motor weakness, or deafferentation pain. Permanent painful numbness (anesthesia

dolorosa) or facial dysesthesia develops in 1% to 10% of patients treated with destructive interventions. Long-term control of trigeminal neuralgia pain is directly related to the degree of permanent postoperative numbness, as are risks of deafferentation complications. Glycerol and GammaKnife rhizotomies performed with local anesthetic, have the lowest rate of postoperative numbness although recurrence rates are high, approximately 50% at 2 years. Radiofrequency rhizotomy, requiring conscious sedation, has the advantage of intraoperative localization to selectively lesion trigeminal divisions, although it produces greater nerve injury and associated hypalgesia, hypesthesia, and risk of deafferentation complications. Long-term pain control or reduction is reported in approximately 60 to 70% of patients. This is similar to results with balloon compression of the gasserian ganglion that is performed under general anesthesia. This injury procedure is preferred for ophthalmic division trigeminal neuralgia, as V1 injury can be achieved with corneal sensation sparing. Most recently, focused radiation to the trigeminal nerve root has become widely utilized, most commonly with GammaKnife, delivering 80 Gy maximal dose. Radiosurgery treats trigeminal neuralgia pain by partial nerve injury just like the other destructive interventions. Unlike the percutaneous needle procedures, however, pain relief usually follows a latency period of 3 weeks to 3 months. The procedure avoids needle-related complications. While a large number of publications report favourable results, only a few have provided long-term follow up and indicate 1/3 of patients will be pain-free and off medications at 5 year follow-up.

A partial microsurgical rhizotomy of the trigeminal nerve root in the posterior fossa is sometimes performed and is advocated by some surgeons when they cannot find the neurovascular compression during attempted microvascular decompression surgery. The rostral third to half of the nerve root is spared to preserve corneal sensation. The pain relief may be long lasting; postoperative deafferentation pain is rare. Other destructive techniques include peripheral nerve injections, avulsions, and sectioning. These simple peripheral nerve procedures provide relatively short-term relief ranging from months to several years and are associated with severe

sensory loss and risk for deafferentation pain. They are generally reserved for those who have sufficient medical comorbidity the other surgical procedures, such as bed-ridden palliative care patients.

Choosing the Right Surgery

The best choice for any individual patient should provide the maximum potential for long-term pain relief with the lowest risk of procedure-related side effects and complications. Unfortunately, these variables are not easily quantified so there is difficulty in weighing the merits of each option. The medical literature does provide outcome results, usually from centres with the high volumes of expertise and experience, a factor to be especially considered for technique-dependent procedures such as microvascular decompression surgery.

Unfortunately, published series may be difficult to interpret and compare, in part because of inconsistency of outcome grading scores. In the recent review of a 175 studies on the four most common ablative neurosurgical techniques for trigeminal neuralgia, only 9 were found to meet adequate data quality criteria. Furthermore, no conclusions about the "best treatment" option could be reached. Physician and surgeon bias clearly plays a key role and are based on their individual experience.

The experience at our centre supports the utilization of the MVD surgery for a majority of the patients with unsatisfactory results from medical treatment for several reasons; highest long-term pain relief or cure rates, lowest risk of facial numbness and lowest risk of major morbidity. This latter item deserves further elaboration as we consider anesthesia dolorosa or life-long dysesthesia seen in 1 to 10% of rhizotomy patients as a major morbidity, in addition to the very small risks of needle-related complications such as intracranial hemorrhage, vascular injury and myocardial infarction reported in the literature. Conversely, risk of major morbidity with MVD surgery in our experience has been exceptionally small. The MVD, however, does require hospitalization and a period of convalescence.

Among the nerve injury procedures, we first offer GammaKnife or percutaneous glycerol rhizotomies, as these are associated with the lowest incidence of facial numbness. The GammaKnife rhizotomy is preferred if immediate pain relief is not required or if there are medical

contraindications to more invasive surgical procedures (e.g. anti-coagulation, unstable ischemic heart disease). Balloon compression is the preferred rhizotomy technique for urgent relief of ophthalmic division pain.

In summary, a patient with trigeminal neuralgia should be thoroughly informed of the anticipated course of their disease and all the management options available.