



Trigeminal Neuralgia Association Australia Incorporated.

ABN 33 914 644 101

OUR MISSION: To advocate for the awareness of Trigeminal Neuralgia and related facial pain.

OUR GOAL: To have a unified understanding of Trigeminal Neuralgia and other related facial pain resulting in better pain management.

OUR VISION: An improved Quality Of Life of a chronic facial pain patient.

Support Groups – Adelaide, Brisbane, Canberra, Coffs Harbour, Gold Coast, Hobart, Melbourne, Newcastle, Sunshine Coast, Sydney, Sydney CBD, Townsville.

June 2010

“Give a man a fish, and you feed him a day. Teach a man to fish, and you feed him for a lifetime.”

Chinese Proverb

As we hold our Annual General Meeting today, it is appropriate to thank all my committee members for their dedication and support. In particular I would like to express my gratitude to **Mr. Frank Martin** who has served as TNA Aus Treasurer since the inception of the national organization in 2003. Frank was instrumental in putting together our constitution and getting the Association registered as a non-profit charity organization. Frank and Norma attended our first Sydney meeting in September 2000, and since then, Frank has been working with me in our TNA work.

After 8 years of counting your money and keeping the Association books, Frank has decided to step down from the Treasurer’s position due to personal health and advancing age. His services and understanding of the Association are invaluable and we are grateful that Frank has kindly accepted to contest for an ordinary committee position and has pledged his continued support.

Once again thanks for renewing your subscription and all donations received. Please be patient regarding a receipt during this transition of Treasurers. I am sure Frank has all bookwork in order to hand over, but the new Treasurer may take a little while to get into stride.

This prompts me to ask - I hope you realise that one day Irene will have to step down too – would YOU be prepared to step up? I am sure there are many out there who can do a better job, while I try. Please don’t hesitate to step forward if you have a desire to run the association. Sorry, no wages, just heaps of gratitude including mine. ☺

Many have expressed appreciation of our monthly newsletters and how you look forward to receiving them. I take heart in knowing that you enjoy reading them but I also hope that other than being an amusement, you do find the communication educational as well. I like to think that having spent 10 years learning about your pain and pain management and communicating with you, I do have some insight. My intention is always to provide you with as many valid tools as possible to help yourself.

A note of apology: I have a stack of letters and emails which I have every intention to respond to but each day the stack gets bigger and higher. Also 3 days comatose in bed with the flu set me back further. I am afraid I may not be able to respond to all your letters especially if they are not urgent. I also appreciate if you should lose your Membership Form – please do not let that stop you from sending in your membership. A note bearing your name, address and date of birth along with your cheque is just as good. Seriously friends, I don’t have the time to send Membership Forms individually. I love hearing from you, but please excuse me if I don’t write back immediately.

Irene.

TNA Aus 4th National Conference 2011 September 2nd – 5th in the Hunter Valley, NSW

- Are you planning on being there? Start saving now. You would hate to miss out.

TOWNSVILLE - inaugural meeting for Trigeminal Neuralgia sufferers and their carers

Date: **Saturday June 19 2010**

Venue: Carville Senior's Villa - Unit Hall
35 - 37 Diprose Street, Pimlico QLD 4812

Time: 13:00 or 1 PM.

Admission is free. Gold coin donation would be appreciated.

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Irene.

DISCLAIMER

The information provided in this Newsletter is of a general nature only and is not intended to replace medical advice. Any views of a medical or therapeutic nature expressed are the views and opinions of the author and are not necessarily the views of Trigeminal Neuralgia Association Australia.

Before considering or undertaking any medical or therapeutic treatment described please seek advice from a Qualified Medical Professional.

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Available at: <http://emedicine.medscape.com/article/248933-overview>.

Trigeminal Neuralgia

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Updated: Sep 30, 2008

Introduction

The clinical description of severe facial pain, which is now known as trigeminal neuralgia (TN), can be traced back more than 300 years. Aretaeus of Cappadocia, known for one of the earliest descriptions of migraine, is credited with the first indication of TN. He described a headache in which "spasms and distortions of the countenance took place." John Fothergill was the first to give a full and accurate description of TN in a paper titled "On a Painful Affliction of the Face," which he presented to the medical society of London in 1773. Nicholas Andre coined the term tic douloureux in 1756.

Idiopathic TN is the most common type of facial pain neuralgia. The pain typically occurs in the distribution of one of the branches of the trigeminal nerve, usually on one side. Rarely, it can affect both sides, although simultaneous bilateral trigeminal neuralgia is uncommon. It involves both the mandibular and maxillary divisions of the trigeminal nerve in 35% of affected patients. Isolated involvement of the ophthalmic division is much less common (2.8% of TN cases).

TN reportedly is one of the most excruciating pain syndromes. It has been known to drive patients with TN to the brink of suicide. The name tic douloureux was first used to describe TN and remains synonymous with the classic form of TN. The tic refers mainly to the visible effects of the brief and paroxysmal pain that, in classic TN, lasts only a few seconds. The pain is so severe that it often causes the patient to wince or make an aversive head movement, as if trying to escape the pain, thus producing an obvious movement, or tic.

An interactive Web site now allows patients to self-diagnose facial pain based on a brief series of questions. An artificial intelligence method (neural network modeling) provides immediate feedback to the patient regarding the diagnosis and patient education resources . [1]

Problem

A lack of clear definitions for facial pain has hampered the understanding of trigeminal neuralgia. The condition has no clear natural history, and no long-term follow-up study of the progression of the disorder has ever been published. In an attempt to rationalize the language of facial pain, recently, a new classification scheme that divides facial pain into several distinct categories was introduced:[2]

- Trigeminal neuralgia type 1 (TN1): This is the classic form of trigeminal neuralgia in which episodic lancinating pain predominates.
- Trigeminal neuralgia type 2 (TN2): This is the atypical form of trigeminal neuralgia in which more constant pains (aching, throbbing, burning) predominate.
- Trigeminal neuropathic pain (TNP): This is pain that results from incidental or accidental injury to the trigeminal nerve or the brain pathways of the trigeminal system.
- Trigeminal deafferentation pain (TDP): This is pain that results from intentional injury to the system in an attempt to treat trigeminal neuralgia. Numbness of the face is a constant part of this syndrome, which has also been referred to as anesthesia dolorosa or one of its variants.

- Symptomatic trigeminal neuralgia (STN): This is trigeminal neuralgia associated with multiple sclerosis (MS).
- Postherpetic neuralgia (PHN): This is chronic facial pain that results from an outbreak of herpes zoster (shingles), usually in the ophthalmic division (V1) of the trigeminal nerve on the face and usually in elderly patients.
- Geniculate neuralgia (GeN): This is typified by episodic lancinating pain felt deep in the ear.
- Glossopharyngeal neuralgia (GPN): This is typified by pain in the tonsillar area or throat, usually triggered by talking or swallowing.

Frequency

The disease begins after age 40 in 90% of patients and is slightly more common in women. The incidence is said to be approximately 4-5 per 100,000 persons, although this is likely an underestimate. TN is observed with increased frequency in one disease category, ie, multiple sclerosis (MS). TN occurs in up to 4% of these patients, in whom it is often bilateral. About 2% of patients with TN have MS.

Etiology

The etiology of most cases of TN is chronic vascular compression and injury to the trigeminal nerve at its entrance into the brainstem (pons). In one study, 64% of the compressing vessels were identified as an artery, most commonly the superior cerebellar (81%). Venous compression was identified in 36% of cases.[3]

Pathophysiology

Vascular compression of the trigeminal nerve appears to cause demyelination and remyelination of the nerve with persisting abnormalities of myelination (dysmyelination).

The most common theoretical explanation for TN proposes that high-frequency ectopic impulses are either generated from or augmented by areas of dysmyelination.[4]These abnormal discharges may ignite a chain reaction of neuronal depolarization in the trigeminal ganglion.[5]The subsequent cascade of neuronal activity is propagated centrally into the trigeminal nucleus and is then perceived by the patient as an overwhelming burst of pain.

Although most cases of TN are caused by vascular compression, other structural disease is present in secondary TN, which can produce either typical or atypical pain. For example, a mass may displace and damage the nerve, resulting in pain. Alternatively, inflammation secondary to multiple processes may be due to the underlying lesion. (See Differentials).

In MS, lesions in the pons at the root entry zone (REZ) of the trigeminal fibers have been demonstrated. This is one form of "symptomatic" trigeminal neuralgia related to visible pathology.

Presentation

TN presents with multiple episodes of severe and spontaneous pain that usually lasts seconds to minutes. The pain is often described as shooting, lancinating, shocklike, or stabbing. The episodes frequently are triggered by painless sensory stimulation to perioral trigger zones, eg, a patch of facial skin, mucosa, or teeth innervated by the ipsilateral trigeminal nerve. Triggers include touch, certain head movements, talking, chewing, swallowing, shaving, brushing teeth, or even a cold draft. The most commonly affected dermatomal zones are innervated by the second and third branches of the trigeminal nerve.

The episodes may be repetitive, recurring, and remitting randomly. Pain-free intervals, which might last for years early in the course of TN, typically grow shorter as the disease progresses. During episodes of pain, some patients have difficulty talking, eating, and maintaining facial hygiene out of fear of triggering the pain.

Physical: Standard bedside neurological examination findings are normal in TN. Patients may refuse examinations of the face, fearing the triggering of pain. Male patients may present with an area of the face, the trigger zone, that is unshaven and unkempt. The finding of numbness in the trigeminal distribution of TN suggests secondary TN and more extensive damage to the trigeminal nerve.

Differentials: Most of the following conditions are not easily confused with TN:

- Trigeminal neuropathy: Sensory loss is usually prominent; pain is slight.
- Herpetic and postherpetic neuralgia (PHN): This condition usually affects the first branch of the trigeminal nerve. The diagnosis of PHN usually requires the outbreak of shingles (herpes zoster) in the forehead or eye. Acute herpetic neuralgia is the norm in shingles, but pain that persists after the lesions have healed is PHN. The risk of PHN development is directly related to patient age.
- Neoplasms: These may present as a compressing mass or neoplastic cell infiltration of the trigeminal nerve. Pain is usually more constant than in TN1, and facial numbness is more common.
- Granulomatous inflammation (eg, tuberculosis, sarcoidosis, Behçet syndrome, collagen vascular diseases): These and other vasculitides may affect the trigeminal nerve and simulate TN.
- Other conditions that may mimic TN include odontogenic pain, geniculate neuralgia, glossopharyngeal neuralgia, temporomandibular disorders, cluster headache, hemicrania, and SUNCT (short-lasting, unilateral neuralgia from headache attacks with conjunctival injection and tearing) syndrome.

Indications

Surgical treatment is indicated for patients whose trigeminal neuralgia (TN) is intractable despite medical therapy, in those who are intolerant to the adverse effects of the medications, and in those in whom previous procedures failed.

Microvascular decompression (MVD) is usually indicated for patients younger than 70 years who are at lower risk for complications during general anesthesia, although healthy older patients can tolerate it well. Percutaneous approaches (eg, radiofrequency ablation, glycerol injection, balloon compression, radiosurgery) are more frequently offered to elderly patients, those in poor medical condition, those with MS, and those in whom previous MVD has failed.

Relevant Anatomy

The trigeminal nerve is the largest of all the cranial nerves. It exits laterally at the mid-pons level and has 2 divisions—a smaller motor root (portion minor) and a larger sensory root (portion major). The motor root supplies the temporalis, pterygoid, tensor tympani, tensor palati, mylohyoid, and anterior belly of the digastric. The motor root also contains sensory nerve fibers that particularly mediate pain sensation.

The gasserian ganglion is located in the trigeminal fossa (Meckel cave) of the petrous bone in the middle cranial fossa. It contains the first-order general somatic sensory fibers that carry pain, temperature, and touch. The peripheral processes of neurons in the ganglion form the 3 divisions of the trigeminal nerve, ie, ophthalmic, maxillary, and mandibular. The ophthalmic division exits the cranium via the superior orbital fissure; the maxillary and mandibular divisions exit via the foramen rotundum and foramen ovale, respectively.

The proprioceptive afferent fibers travel with the efferent and afferent roots. They are peripheral processes of unipolar neurons located centrally in the mesencephalic nucleus of the trigeminal nerve.

Workup

Laboratory Studies

- The diagnosis of facial pain is almost entirely based on the patient's history. In most cases of facial pain, no specific laboratory tests are needed. A blood count and liver function tests are required if

therapy with carbamazepine is contemplated. Oxycarbazine can cause hyponatremia, so the serum sodium should be tested after institution of therapy.

- Although rarely indicated, appropriate blood work for rheumatic diseases, such as scleroderma (trigeminal neuropathy is reported in up to 5% of patients with this collagen vascular disease) and systemic lupus erythematosus, should be undertaken in patients with atypical features of facial pain and a systemic presentation of collagen vascular disease. Appropriate blood work includes a sedimentation rate, antinuclear antibody titer, double-stranded DNA, anti-Sm antibody, lupus erythematosus cell preparation, and complete blood count to look for hematological abnormalities (eg, hemolytic anemia, leukopenia, thrombocytopenia). Particularly in the case of scleroderma, creatinine kinase and aldolase levels may be elevated with muscle involvement. Antibody titers to SCL-86 and SCL-70 may also be present.
- When surgical procedures are contemplated, appropriate and routine preoperative laboratory tests are in order.

Imaging Studies

- In cases of typical (TN1) and atypical TN (TN2), a brain MRI with contrast is required. An MRI is sensitive for the exclusion of intracranial lesions that can rarely cause trigeminal neuralgia.
- Obtain contrast-enhanced brain MRIs prior to surgery to evaluate for vascular malformations or other lesions. Devote particular attention to the posterior fossa. High-resolution imaging of the nerve at the brainstem entry zone may reveal vascular compression of the nerve.[3]
- Imaging procedures have improved to the degree that reliably imaging neurovascular compression of the trigeminal nerve using high-resolution MRI sequences is possible.[6]

Treatment

Medical Therapy

The most effective medication for the treatment of trigeminal neuralgia (TN) is carbamazepine. It acts by inhibiting the neuronal sodium channel activity, thereby reducing the excitability of neurons. The effective dose ranges from 600-1200 mg/d, with serum concentrations between 40-100 mcg/mL. However, many adverse CNS effects (eg, vertigo, sedation, ataxia, diplopia) are associated with carbamazepine, which may make it difficult to use in elderly patients. The dose may be tapered once pain is controlled, since remission may occur.

Obtain a blood count during the first few weeks of therapy and yearly thereafter. Agranulocytosis and aplastic anemia are extremely rare adverse effects, but suppression of the WBC count in the range of 200-3000 $10^3/\mu\text{L}$ is not uncommon. This mild suppression of the WBC count does not warrant discontinuation of carbamazepine therapy. Hepatic function should also be monitored. Up to 70% of patients receive complete or acceptable partial relief, at least temporarily.

Oxycarbazine is a newer agent that may have fewer side effects, but it can cause hyponatremia, which should be monitored with serial serum sodium measurements in the first few weeks of therapy.

Gabapentin, lamotrigine, topiramate, and several other newer anticonvulsants are being used to treat trigeminal neuralgia. Further outcome studies on their use in the treatment of trigeminal neuralgia are needed.

Surgical Therapy

In some studies, more than 50% of patients with TN eventually had some kind of surgical procedure. Experience would indicate that medical management eventually fails in most patients with TN, and those patients undergo surgery.

Microvascular decompression (MVD) is the classic and most effective surgical procedure. It involves a posterior fossa craniotomy and dissection of vascular elements that compress the trigeminal nerve in the subarachnoid space. Teflon felt is used to pad the nerve away from the offending artery or vein.

The effectiveness of MVD is based on the hypothesis that compression from vessels in the vicinity of the trigeminal nerve leads to abnormal nerve activity.

Percutaneous approaches

- **Radiofrequency (RF) rhizotomy** (thermocoagulation): This is an outpatient procedure performed by placing a needle into the gasserian ganglion, through which an electrical current passes, heating the probe and producing a thermal lesion in the ganglion. The reported rate of pain recurrence is the lowest compared with other percutaneous procedures, with the average patient experiencing 3 years of excellent pain relief.[7]Complications of RF rhizotomy depend on the amount of numbness created by the lesion. Dysesthesia has been reported in up to 5-25% of patients, corneal numbness in up to 15%, and masseter weakness in about 4%. These complications are markedly reduced if the numbness produced by the procedure is limited. Some of these complications may be reversible. To avoid ophthalmic complications, some experts do not recommend this approach when the ophthalmic division is involved.[8]
- **Glycerol rhizotomy**: The rate of pain recurrence with percutaneous rhizotomy is between that of radiofrequency ablation and percutaneous compression. The rate of significant facial numbness (5%) is low. About half of the patients have pain recurrence at 2 years.[9]
- **Percutaneous balloon microcompression**: Recent studies indicate that this procedure carries about the same complications and average pain-free outcome as glycerol rhizotomy (2 y).[10,11]
- **Gamma knife radiosurgery (GKRS)**: This is the least invasive procedure. Administered as a single dose of 70-90 Gy delivered to the trigeminal root, this procedure is an option when medical and surgical techniques fail. Contemporary studies indicate that the average pain-free outcome of GKRS is about the same as for RF rhizotomy, or around 3 years.[12,13]
- **Other procedures**
 - Peripheral neurectomy, although safe and effective, is rarely used but may be of value in patients who have TN and a limited life span.[14]
 - Trigeminal tractotomy (cutting of the descending trigeminal tract in the medulla), retrogasserian glycerol instillation in trigeminal cistern, peripheral alcohol blocks, and partial trigeminal rhizotomy via a posterior fossa craniotomy are other rarely used options.

Complications

Morbidity associated with trigeminal nerve decompression stems from hemorrhage, infection, and possible damage to the brainstem around the area of decompression.

In centers where MVD is frequently performed, complications include facial dysesthesia (0.3%), facial numbness (0.15%), cerebellar injuries and hearing loss (<1%), and CSF leakage (<2%).

With thermocoagulation, dysesthesia can occur in 5-25% of patients, although this complication is uncommon when the degree of facial numbness is controlled. Corneal numbness can occur in up to 15% of patients, and masseter weakness can occur in about 4%. Many of these complications are reversible over time.

Outcome and Prognosis

Accurate data on surgical outcome are still difficult to obtain. Most surgical series do not meet modern criteria for evidence-based medicine. Recently, an evidence-based approach has been applied to both the diagnosis of trigeminal neuralgia, and its surgical management. These results were published in the journal *Neurology* in August 2008 and can be viewed at Medscape.

The challenges of the field are exemplified by a paper published by Zakrzewska and Lopez.[15]They assessed the quality of 222 reports of surgical management of trigeminal neuralgia and found only 3

randomized controlled trials (RCTs) on peripheral techniques. The vast majority of the evidence was of case series reports (class 3 evidence), and a very high proportion was of poor quality.

The difficulties center around the following important issues:

- Lack of clear diagnostic criteria and baseline assessments
- Poor methodology - Low numbers, short follow-up period, high percentage lost to follow-up, mixture of cases (eg, previous surgery, including repeated treatments)
- Lack of Kaplan-Meier assessment of pain relief, poorly defined outcome measures (eg, partial success), incomplete reporting of all complications, and no quality-of-life evaluations
- Lack of independent evaluation

Certain principles seem to transcend even the relatively poor outcomes studies performed thus far on procedures for trigeminal neuralgia. The chance of success is seemingly less likely the longer the duration of symptoms. Of all the procedures, MVD carries the lowest rate of facial dysesthesia at 0.3%. Facial numbness caused by MVD is not common (0.15%) compared with that caused by the percutaneous procedures; in addition, MVD is the procedure of choice in younger patients who desire no sensory deficit. MVD is also the most likely treatment to provide sustained postoperative pain relief.

One study found that 70% of patients had excellent results (defined as a cure or significant pain relief) 10 years after the procedure, with a recurrence rate of less than 1%.^[16] Possible reasons for failure include new vascular compression from scarred implants or other sources, but these are rarely identified during posterior fossa re-exploration for failed MVD. After an initial 10% risk of recurrence of TN within one year after MVD, the risk of pain recurrence is about 3.5% every succeeding year.^[17] The reasons for this recurrence are not clear.

In a 1999 study, cerebellar injuries and hearing loss occurred in less than 1% of the patients, and CSF leakage occurred in 1.85%.^[18] As expected, these complication rates were inversely proportional to the total number of procedures performed.

Future and Controversies

Once developed, trigeminal neuralgia (TN) is likely to have an exacerbating and remitting course. Over time, the pain-free intervals appear to diminish, and the pain becomes progressively more medically intractable. Temporary spontaneous remission may occur at any time, but permanent remission never occurs.

Without treatment, typical TN (TN1) may transform over time to become atypical TN (TN2), with a change in the character of the pain to more constant and background pain and the development of sensory impairment. Therefore, some authorities recommend early intervention to give the opportunity of pain relief without sensory deficits.

Have fun with Riddles:

1. Though not a plant, Has leaves. Though not a beast, Has spine.
Though many wouldn't need this thing 'Tis more valuable than wine.
What is it?
2. Around the corner there is a tree. Under the tree there is a school. In the school there is a desk.
Behind the desk there is a bell. Behind the desk is a teacher.
What is her name?
3. What has a foot on each side and one in the middle?

SYDNEY SUPPORT GROUP
Toongabbie Public School
1st May 2010

Present: Irene W, Peter & Rose H., Kim S, Kim K, Marion, Stuart & Gundel, Frank, Henry & Jeanette, Ann & Laurie, Jan, Marj & Ken, Vera.

Apologies: Jocelyn, Andrew B, Irene V, Stephanie R & Vern R; Hilary and Keith W.

Irene W opened the meeting at 1.30 and noted it was good to see everyone making the effort to arrive early, before the scheduled starting time of the meeting.

Irene advised that Bernice had called to say she was doing well after her successful MVD in February, which we were pleased to hear the news.

Marion reports she is still going well, after her MVD by Dr Dexter in July 2008 and has absolutely no side effects. She just takes B12, 1000mcg daily.

Jeannette finally has something to report! As most of us know Jeannette was scheduled for MVD surgery some years ago, but suffered a stroke which actually got rid of her TN! She had received a letter from Dr Dexter recently asking her to attend the Clinic for an MRI. She has had the MRI and is due to see Dr Dexter for the results in the next couple of weeks. She is rather intrigued as to why he had requested this MRI, as she has NO PAIN.

Ann is doing OK, she still "feels" swollen and numb, on one side of her face with sometimes the 'creepy crawly" feeling, but has no pain. She had Radiofrequency in 1999. Although she feels one of her cheek is swollen, there is no physical evidence. She gets a bit tongue tied at times.

Vera has had no problems in 4 years following a successful MVD, after having suffered TN for 25 years.

Marj said she is not too bad. Her doc. has changed her Tegretol to slow release 300mg per night & 300mg in the morning. She feels a bit sick when she eats, plus has electric shocks. She is on Epilim, but doesn't think it is helping. She had a dental check up & her teeth are good. Marj was a bit concerned going to the dentist and Irene suggested that if contact details of her Dentist was provided to the Association, we will send TN information and our newsletter to her dentist – keeping him informed and updated of TN.

Irene asked Marj If she persists in eating/ chewing - does the pain ease? Others have suggested that after some minutes of "chewing over pain" – it becomes easier to eat /chew.

Irene suggests trying topical **Amethocaine gel**

Marj also said her right hand is useless - the after effects of Radiotherapy following prior Surgery for another medical condition. Irene explained the use of "mirror therapy" in phantom limb pain, explained the concept and thought perhaps Marj could try it.

Peter suffers from Post Herpetic Neuralgia and has 2 nerve stimulators implanted in his face. He has been up & down and says he has had a lot of stress at work. He still leaves the stimulator on all day & hasn't been back to see if it needs re programming.

Jan is still good, no pain following MVD in 2008. She met a lady in the Supermarket at Easter who also suffers TN and gave her a newsletter, but didn't get her contact details. She has been keeping an eye out for her since.

We welcomed new member, Julie & her husband Steven.

Julie has just been diagnosed and has been suffering for 3 weeks, CONSTANTLY.

She has had a lot of Oral Surgery in the past and then contracted a Respiratory Infection and that is when the pain started with electric shocks above her right eye. She did the rounds of Drs and ended up in emergency where they diagnosed a "headache". The Hospital did mention TN, briefly, but discounted it, she doesn't know why. Julie then basically self diagnosed on the Internet. She requested a referral to Dr Russell Vickers, whom she had seen previously for a phantom tooth pain and he confirmed TN and prescribed Neurontin, last Wednesday. So far the pain is increasing, she is lucky if she has 2 minutes pain free each day and she is struggling to deal with the situation as she can't eat & is getting very down. She started on 1x Gabapentin on Thurs, then 2 on Fri & will take 3 today, but so far she has had no relief. She has some Zostrix, but has not tried it as yet as she does suffer from allergies, so is not sure if she should try it. She was obviously in a lot of pain and we could all sympathise with her & felt every zap, along with her!

We offered various suggestions for eating (using a straw, placing food as far back on her tongue as she can, eating high nutritional value foods etc)

Irene suggested contacting Bob Harrison, compounding chemist on 02 95247200 to get some compounded methylcobalamin. We wish you well Julie, and hope that you have gained some valuable information from those present today.

Celia has had a severe attack, after living with TN for 10 years, but usually only having a couple of quick zaps each day. She saw her Neurologist the day after who put her on Gabapentin, 1 x day, which has helped, however she feels it may be time to see Dr Dexter & is considering surgery. Good luck Celia.

Kim S is mostly good, she had 2 severe episodes in the last few months, 2 different types of pain. One was sharp shooting and the other was a burning type attack, but she has had lots of pain free days so is happy about that.

Kim K is going OK, she keeps busy & avoids known triggers.

Stuart reports he is about the same. He suffers from A.D. He has changed back to Amitriptyline from Nortriptyline as he finds his mental alertness is better and he sleeps a lot better and it doesn't seem to make much difference to his pain level.

Henry & Jeannette supplied 2 Mothers Day Raffles today that were won by Kim S & Ann.

Irene W closed the meeting at 3.00pm, and we enjoyed a cuppa and chat.

Our next meeting will be on **Saturday 3rd July 2010**. at 1:30pm
Guest Speaker is a Chinese doctor. Topic: "**Trigeminal Neuralgia in Chinese.**"

Thanks Marion for the meeting notes. *Irene.*

Our thoughts are with Hilary – undergoing surgery for her back.

Have you any helpful tips to share

Have you any neat tricks to help other sufferers overcome their difficult time? Eg: often many struggle to eat or chew - how did you manage to "eat" your food? I would like to build a list of helpful tricks to share with new/old sufferers. Please send them to me – Irene

Are you on B12??

Be it cyanocobalamin / methylcobalamin / hydroxocobalamin (Neo B12 .)

I know many in our Association are managing your TN with vit.B12 - it would be nice to know how many.

Please drop me a line with: a) **type of B12**, b) **strength of B12** & how often c) are you taking **TN medication?** d) **name your medication/s** e) **the dose** f) **has B12 helped?** g) **your TN history.**

All comments welcome. - Irene.

Brisbane Support Group
30 Ridley Road, BRIDGEMAN DOWN
8th May 2010 1:30PM

Attendance: Henry C, Eileen C, Lorraine B, Jeff B, Margaret B, Colin B, Helen W, Ian W, Mary M, Noela W, Doreen T, Margaret H, Tony M

Apologies: Leonie G, Lorraine G, Joan F

Our meeting opened with our expression of joy in having Colin with us following his recent illness.

The widespread use of methyl cobalamin injections for children with autism was discussed. One large treatment program in the US is currently overseeing this medication used on 75000 patients. Some children are given doses several times a week, by their parents, as the little ones sleep. Tony spoke of his ongoing contact with parents and doctors in this program.

We then shared our stories.

Leonie has passed on that her mum Corrie is continuing to be really well. She has switched to methyl cobalamin injections following neocobalamin. This significantly reduced pain state means that she no longer requires morphine and continues her adventurous travels visiting the family. This extended reduced pain state follows two failed MVD's, numerous procedures and medications. We send our wishes for your ongoing healing, Corrie

Joan sent in an apology, passing on that she continues to be essentially pain free since commencing methyl cobalamin injections seven years ago. Her bouts of TN pain had been so bad that she had to stop work. She no longer uses TN pain medication.

Henry had suffered severe TN pain for ten years while on Tegretol. Since commencing neocobalamin injections, he is essentially pain free. He commenced using fortnightly injections, and now monthly. Minor twinges come in times of stress, particularly if he is late for a shot. He is off all TN medication and says he only comes to the meetings just to skate!

Lorraine is now off Lyrica and down to a low tegretol dose. She says the monthly methyl cobalamin injections definitely help.

Margaret's TN continues to be at bay. Even the recent period of concern through Colin's treatment did not trigger the TN. She increased her vitamin therapy to assist with combating the added stress. Since commencing neocobalamin injections, she has reduced her medication from 22 tablets to just 400 mg Tegretol. She would love to now go off it completely and sees it as a crutch. Colin told us he is now well following his recent surgery.

Helen's TN was recently very bad and tried a combination of Tegretol, Neurontin, Epilem and morphine with no control of pain prior to her MVD, which occurred on March 22. She spent four weeks in the Wesley Hospital, including two weeks prior while medication options were being explored. She also had her MRI at this hospital. She is extremely happy with Dr Coyne's care and is now TN pain free. There is some numbness around the ear, but hearing is fine. Medication is now just 400mg Tegretol.

Mary says she is great. She previously was on ten 300mg Neurontin, but has reduced that to just two per day with 25 mg Endep at night, which seems to dampen anxiety levels. She is on methyl cobalamin lozenges and magnesium and has had no zaps for two months. We wish Mary safe travels as she heads for London, Paris and Africa.

Noela is now really well. She is no longer getting acupuncture. She is on monthly methyl cobalamin injections and takes no medication.

Doreen is going really well also. She did experience a lapse with recent dental work, but all is now well. She continues with neocobalamin injections and magnesium and now takes a half of a 100 mg tegretol morning and night. She intends to further reduce this dose.

Things have been really bad for **Margaret** for past four months. She had experienced a significant pain free period following the commencement of monthly methyl cobalamin injections. There is serious eye pain as well. Current medication is 800mg tegretol, previously 2000mg prior to methyl cobalamin. Margaret has noticed the hot climate up here affects her TN more so than down south. She is going to try eliminating coffee and chocolate.

Tony has experienced some pain, but the cycle was short lived. He continues monthly methyl cobalamin injections and has been on a homeopathic remedy as well. He is on no standard TN medication and is now back to part time work.

The homeopathic practitioner has treated many TN patients and claims a success rate of 80%.He has offered to speak at a future meeting. (*would be good if the "many" knows about TNA Aus too ☺ – Irene*)

Thanks again to all for our beaut afternoon tea.

We don't say this often enough, but thanks so much to Irene for her constant dedication and vision in leading our association. The pioneering work with B12 has lead many to wellness.

To all who could not be with us today, we trust your burden is not too heavy, and look forward to your return. You missed some good cakes!

I have passed on our thanks for the prayers of Fr John and his parish for our group. Sounds like they're being answered.

Gold coin collection\$25

Next meeting: Saturday July 10

Tony MacPherson

**Sunshine Coast Support Group
Kawana Library, Nanyima Street, Buddina.
Saturday 15th May 1.00pm**

Present: Jean W, Jill LeM, Patricia O, Max H, Sherryl M, Lloyd K, Andrea F, Trixie & Keith B.

Apologies: David & Gloria G, Jim K and Teresa M.

Guest speaker: Drew Glendinning. Special welcome to our guest speaker. Drew is a Doctor of Chiropractic (USA), he specializes in the upper cervical.

Reports from members

Jill Lem: Still having zaps. She has changed from Lyrica to Tegretol. Tegretol is already effecting her liver. It's not slow release. Jill went to Noosa and had an Xray and she thinks it was a close cut.

Patricia LeM: She has been crook for the last two months. Went to see another Doctor who placed her on Toleraid and Lyrica. Lyrica helped her headaches and they are now much milder. Patricia is also taking Cymbalta 30mg. At this stage Patricia hasn't been diagnosed with Trigeminal Neuralgia

Andrea F: Andrea has had Xray's on her teeth and they are perfect. She is thinking about having the operation. Her medications are Lyrica and Tegretol.

Trixie B: We couldn't wipe the smile off her face. Trixie had a MVD in February. She hasn't had one pain since the point of the operation. Had a CT scan 2 weeks ago and it showed a long droopy nerve. Dr Dexter is more than confident that this shouldn't return. In all Trixie was in hospital for 1 week. After

three weeks she was able to slowly wean herself off the medications. There is no numbness to her face at all. What a great outcome for Trixie:)

Keith B: Is so happy to get is wife back.

Lloyd K: His operation was 2 years ago this September. It's like he never had Trigeminal Neuralgia.

Max H: Has been able to cut back on his Tegretol from 800 to 200. He is now practically pain free and quite happy with life at the moment.

Sheryl M: Sheryl was diagnosed 16 years ago. She had surgery and was pain free for 2 years before it came back. Had radiation on her nerve and is a little droopy on one side of her face. She had a MRI and there is no obvious damage that has shown up. The pain is coming back as the weather is getting colder. Sheryl's pain is manageable.

Jean W: She feels that the Arachnoid cyst may have returned due to increasing headaches. May have to go back to see Dr Dexter. *(Sorry to learn that your symptoms are back – Irene)*

Drew spoke about what he does as an upper cervical chiropractor, specializing in the upper neck. He gave a very informative talk some of his points were:

* He asked if any of us had been in an accident, whiplash, fallen off our bikes etc? If you have a upper neck problem, then there is chance the TN nerve is compromised.

* We go to the dentist and doctor for a check up, but we don't do anything about having our upper spine checked out. (Food for thought).

Everyone was asked to stay for a cuppa and something to eat. Thanks to everyone who helped set up and pack up. Many hands make light work.

Next Meeting: 17th July.

Jean W.

HOBART SUPPORT GROUP

Glenorchy Library

16 May 2010 11.30am-3pm

This meeting was unlike those held previously because Dr Arun Aggarwal was our special guest. It was promoted as a professional development seminar to the dental and medical professions and other health professionals including osteopaths and acupuncturists. In addition, it was promoted to sufferers and their carers and supporters as a chance to learn more about their pain and its management.

Apart from the generosity of Dr Aggarwal making the visit, many people contributed to the seminar's success. The two Co-Group Leaders, Helen T and Ros W worked tirelessly to contact all the medical, dental and other health associations in Tasmania to persuade them to encourage their members to attend. Ros was particularly active in her contacts with radio and TV, and Helen got an informative article and photo in a Hobart newspaper. Sufferers who had previously contacted the Support Group were armed with flyers and actively canvassed their GPs, neurologists and other health professionals, and talked to whoever would listen. Then everyone who had been previously connected with the Group made wonderful platters of healthy sandwiches and other light tasty food for lunch. Ian W and Ros W came in a day early and set up the furniture. Del L, ably supported by wife Jean, was a star and organised the milk, tea and coffee ... and then made hot drinks for dozens of people! Sue Brierley chauffeured Dr Aggarwal to and from the airport. It was a team effort and, collectively, these efforts bore wonderful fruit. Almost 60 people attended the session; people travelled from the northwest coast

and the north of Tasmania. Approximately a dozen people were health professionals. These included a neurologist, a periodontist, a couple of nurses, an acupuncturist, two dental therapists, and two dentists one of which runs a practice restricted to the treatment of Orofacial Pain, TMJ Disorders, Oral Medicine, Oral Surgery, and Dental Sleep Medicine. This turn up was very exciting because we can see there are some local professionals who want to learn more about TN. It gives us hope. We are yet to phone everyone who attended to learn more about their backgrounds and situation.

Before the presentation commenced, everyone enjoyed a healthy lunch, and the opportunity to meet each other and have a chat. Photocopies of membership application forms for the TNA were thrust into everyone's hands, as was a flyer about our Hobart Support Group. Non members were encouraged to join.

The formal part of the meeting started with Co-Group Leader Helen T warmly welcoming everyone, explaining the reason for the seminar and how Dr Aggarwal came to agree to visit, and then describing how the seminar would work. Dr Aggarwal gave two Powerpoint presentations; the first focussed on the diagnosis of facial pain and he alerted the audience to the fact there are 140 types of facial/head neuralgias. It was clear that doctors must ask the right questions to make their diagnosis, and sufferers must give detailed descriptions of where and when their pain occurs so that the correct diagnosis can be made. This first presentation was followed by a short break, in which people wrote down their questions (this helped those who were in pain or who were shy to have a voice). The second session was devoted to treatments by drugs and electrophysiological investigations. An active question time followed, before the afternoon was wrapped up, Dr Aggarwal was thanked, and he left to fly back to the mainland. We agreed Dr Aggarwal's presentation was marvellous and we were all very appreciative of his significant contribution to raising knowledge and understanding of TN in Tasmania. Everyone enjoyed a cuppa and social chat before leaving.

Next meeting: Saturday 14th August 1.45pm for 2pm start. Finish time will be 4pm. We will be inviting another special guest. Further details will be posted out to members when available. Always feel comfortable to contact Group Leaders Helen on 6245 0429 or Ros on 6234 7989.

Please note: with Christmas in mind, the final gathering for the year will be on Saturday 20th November 1.45pm for 2pm start. Finish time will be 4pm.

Helen & Ros

**ADELAIDE SUPPORT GROUP
BURNSIDE CIVIC CENTRE
SUNDAY 30th MAY, 2010**

PRESENT: Bert J, Eileen P & Friend Jean, Kevin S, Garry & Lisa R, Joan E, Sylvia, Sue and David H, Grace A, Graham & Liz B. Ann T, June & Roger O, Jill W,
APOLOGIES: Marie F; Jan S

DONATIONS: \$46.00. Expenditure: Projector Hire \$120, Milk / Coffee \$5.45. On Hand \$93.65.

WELCOME: Graham welcomed members with a special welcome to Sue and David H attending for the first time and guest speaker Andrew Zacest.

Graham introduced our guest speaker for the afternoon, Andrew Zacest Neurosurgeon at RAH and TNA Aus Medical Advisory Board Member. Graham commented how fortunate we are to have Dr Zacest with his expertise in TN, resident in Adelaide and more so that he is willing to talk to our group on a Sunday afternoon.

The theme of the presentation was "Which treatment is right for me?" Dr Zacest covered the different surgical procedures available to TN sufferers, the points to be considered when contemplating surgery

and the pros and cons of each procedure. He stressed the need for having a proper diagnosis to determine whether it is Classic Trigeminal Neuralgia and whether it is type 1 or type 2 as certain treatments are not as effective with type 2 TN. He also briefly covered other facial pain complaints which have similar symptoms to TN and what the best remedy might be.

The session included a video of an actual MVD being performed. Dr Zacest then took questions from the floor. At the conclusion of what had been a very informative and enlightening presentation Graham thanked Dr Zacest and presented him with a bottle of wine.

MEMBERS UPDATE:

EILEEN: underwent a radiofrequency rhizotomy early April. She reported some numbness and sensitivity, which is nothing compared to the pain she was having. She is very happy with the result and would not hesitate to have another rhizotomy if it became necessary. She was pain free immediately on completion of the procedure and is now medication free.

BERT: Is taking 600 mg. Tegretol daily. He saw a chiropractor (same as Kevin S) but was told he would not be able to help him. He is undergoing a radiofrequency rhizotomy in June. We wish him well.

KEVIN: Has suffered TN for 15 years, off and on. He has been receiving chiropractic treatment lately and after several treatments is having considerable relief. He is not sure if he has TN as he feels it is more muscular. His neurologist is also not sure if he has TN.

JUNE: Is coming off Gabapentin. Her pain seems less now she has reduced the dosage. Her GP does not want her to “rush” into anything and seems to have a negative slant regarding surgical procedures. It was obvious June was experiencing “shocks” while she was talking to the group. The group encouraged her to request a referral to see a neurologist.

SUE: Attending the group for the first time with her husband David. Her TN is very recent, 6 weeks, commencing during a holiday in Tasmania. She attended the Hospital Emergency Dept where a young intern diagnosed TN and prescribed Tegretol. Sue had experienced sensitivity for several months before her initial full blown attack. She was placed on a high dose of Tegretol initially which left her in a “zombie” state. She now takes 100 mg. daily which she copes with, however her pain is breaking through. Graham loaned her Striking Back and she will consider seeking specialist help.

JILL: Takes 600 mg. Tegretol, increasing to 800 mg. when necessary. She is persevering with acupuncture and physiotherapy. She still experiences pain, but not the electric shocks. She can now clean her teeth and apply her makeup without crying with pain. She has ceased taking Oxycontin.

GRACE: After two cutaneous procedures has continual numbness. Her plan of action should the electric shocks return is to undergo an MVD.

JOAN: Continues to be really well. It is wonderful that Joan continues to attend the support group even though she does no longer suffer TN. She gives everyone much encouragement.

GARY: Takes 1200 mg. Nurontin. He has a lot of pain in his eye and is seeing an eye specialist at the RAH. He finds it hard to understand what triggers his pain when he can be sitting, completely relaxed in his arm chair and suddenly he is racked with pain.

ANN: Still has her good days and bad days. She takes magnesium which helps control her spasms and recommends taking it at night. She has been going to a physiotherapist which she finds helpful.

GRAHAM: Continues to be completely pain free – 10 months since his MVD.

OTHER BUSINESS: Graham reminded members to check that their membership subscriptions were up to date. Graham advised that he and Liz were departing for overseas on Tuesday and they will not

return until August. However there will be a meeting as scheduled on Sunday 25th July 10 which Ann and Bert will organise.

MEETING CLOSED AT 3.45 p.m. followed by the usual cuppa and chat with lots of cakes which many members had kindly supplied.

NEXT MEETING: **SUNDAY 25th July, 2010** at 2.00 p.m. Burnside Town Hall – Civic Centre

Graham and Liz B

Correspondence Corner

David: I had the MVD and felt pretty good, was walking well but perhaps still a little groggy and lacking in concentration. I had the 29 staples removed from the incision which had healed very well. On being asked I told the doctor that I was fine except I had this annoying drip from my nose. He discharged me and I went home. 4 hours later I received a phone call from the hospital asking me to return as soon as possible. Dr told me that the fluid was cerebral spinal fluid and was escaping from the wound and draining out through the nose. I was put on tablets to try and stop it, and also had a drain inserted into the spine to collect and slow down the fluid leak.

Unfortunately the drain touched a nerve in the spine which gave me excruciating pain in my left leg, such that I could not move it without agony. I was in such pain that I could not eat or drink much and my condition deteriorated drastically. When the catheter was removed after week to my great relief, I found that my left heel had a huge, painful bed sore, a result of my week in bed not being able to move my leg. Sadly although much reduced, the drip from the nose was still there and would be possible for infection to enter the skull which could develop into meningitis. So doc decided to reopen the original incision and reseal the area again. Test showed that I had developed small clots in my leg and lungs so before he could operate again a filter was inserted into my vein to catch any clots before they could do any damage.

A couple of days after the operation they went to take out the filter but found that it had been very successful at doing its job, and that it contained a significant amount of clot material. So it was decided that it was too dangerous to remove in case the clots dispersed and went to a critical organ. I was put on clot dissolving injections for 12 days. and after this they were able to remove the filter successfully.

By this time the bed sore on my heel had become an open wound which required constant dressing, and prevented me from putting my heel to the floor. I was able to walk on tip toes but not being a ballet dancer I found that it soon became painful and greatly affected my balance. Once the filter and my 39 staples had been removed and a bed was available, I was moved to where there was a specialist wound clinic and physiotherapy for my walking and balance therapy. After 2 weeks I was allowed to go home but needed the Community Nurses every second day to dress the wound, and to return to Wound Clinic a couple of times.

The wound has now healed completely over and I am just starting to put my heel gingerly to the floor and learning how to walk normally after walking on tip toe for a long time. The muscles in my feet have lost a lot of condition because they soon ache after a very short walk.

Yes the MVD operation seems to have been a success in that I have no pain or drippy nose. However I can see that it will be couple of months before I am walking properly and confident enough to return to tennis without the chance of damaging the very fragile skin on the heel. Having been a top fund contributor to MBF for very many years I believed that all costs incurred in hospital were covered. I now find that this is not the case and the final bill for all the blood tests and scans etc. is coming out to about \$9000.

** I am sorry to learn of the problems you have had since the MVD. Yes, Doctors do warn of CSF leak - less than 2% with MVD surgery; but what CSF leaks entails is rarely expanded. The positive thing is that your MVD has stopped the TN pain, and with time, I am sure you will soon be back with your tennis. Irene.*

2010 Meeting Dates

State	GROUP	Date & Time	Venue	Group Leader/s
ACT	Canberra	24 July 10.30-12.30	Barbara Byrne Room Labour Club, Belconnen	Jan Goleby ☎ 02 62474508
NSW	Sydney	3 July 1:30pm – 4:00 pm	Toongabbie Public School Cnr Fitzwilliam & Binalong Roads	Irene Wood ☎ 0413 363 143 Kim Koh ☎ 02 97431279
	Sydney CBD	7 August 10:00am –12:30 pm	St. James Parish Hall, Level ONE, 169 Phillip St. Sydney CBD	Irene Wood ☎ 0413 363 143
QLD	Brisbane	10 July 1.30-4.00pm	30 Ridley Road BRIDGEMAN DOWN	Leonie Gall ☎ 0407 55 44 07 Tony MacPherson ☎ 07 3822 2286
	Sunshine Coast	17 July 1:00 pm	Kawana Library, Nanyima Street, Buddina	Teresa Miller ☎ 07 54912487 Jean Williams ☎ 07 54911978
	Townsville	19 June 1.00 pm	Carville Senior's Villa 35 – 37 Diprose St PIMLICO	☎ Irene Wood ☎ Sera 07 47516415
S.A	Adelaide	25 th July 2:00pm – 4:00pm	Burnside Town Hall Civic Centre Cnr Portrush/Greenhill Road Guest: Dr. Andrew Zacest	Graham/ Liz Boyer ☎ 08 8392 2781
TAS	Hobart	14 August 12:30 – 2:30 pm	Glenorchy Library Enter via Barry and Cadell Streets	Helen Tyzack ☎ 08 6245 0429 Ros Wilkinson ☎ 08 6234 7989
VIC	Melbourne	12 June 1:30pm – 4:00pm	"Ringwood Room" Ringwood Library, RINGWOOD	Evelyn Diradji ☎ 03 9802 6034

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