



# *Trigeminal Neuralgia Association Australia Incorporated.* ABN 33 914 644 101

## *Making A Difference*

**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.

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

## April 2012

### **MOVIE AND SUPPER NIGHT**

**THURSDAY 3rd of MAY 2012** around 8pm Tickets are expected to be about \$40 per person.

We are planning a MOVIE AND SUPPER NIGHT to raise money and awareness of trigeminal neuralgia and Trigeminal Neuralgia Association.

Please Keep THURSDAY 3rd MAY 2012 around 8pm – & bring family and friends to our movie and supper night. A great cause to support!! We will let you know movie title soon as the cinema informs us. But for now, we need you to book in that date with your friends. We would hate for you to miss it “because of any previous engagement.”

Mary Zaccaria has worked hard in putting this together. Come and Share a delightful evening with us and support our cause.

### **REGIONAL CONFERENCE IN ADELAIDE: 28<sup>th</sup> of April 2012 from 9AM – 5 PM**

“Pain is inevitable, suffering is optional” – Buddhist saying.

My passion for starting TN support groups, founding a national TN support association and hosting conferences, has always been to provide you with information. My desire is to empower you with the information so that you can better plan your pain management. In my opinion inaccurately presented information can lead to wrong decisions and that is worse than being ignorant of the fact. I am proud to say that many folks have been able to seek appropriate treatment from the knowledge gained, and are now pain free, if not, managing their pain with more authority.

A conference offers direct learning from experts who treat TN and facial pain regularly. It is a fantastic opportunity for you to learn and to be able to make decisions on your pain management. I strongly urge you to know your options well. Learn all you can about what is available and how to avoid taking unnecessary risks.

I would also like to thank the Adelaide Support Group for the generous donation of \$200 for SA Regional Conference to be held in April. This money will help pay part of the Lecture Hall hire.

### **WELCOME TO SYDNEY - DR MARK LINSKEY**

Neurosurgeon, Dr Mark E. Linskey, Associate Professor and Chairman of the Department of Neurological Surgery at UCI (California USA) is currently in Sydney for the Leksell Gamma Knife Society Meeting and has offered to speak at our Sydney CBD meeting on the 31st of March, St James Parish Hall 10:00 AM – 12:30PM.

Dr Linskey is also the Western Regional Director, MAB, TNA-The Facial Pain Association.

Among his many works is his collaboration with Prof Joanna M Zakrzewska; in 2009 and 2008 : Trigeminal neuralgia - Clinical evidence; and A prospective cohort study of microvascular decompression and Gamma Knife surgery in patients with trigeminal neuralgia.

We are inspired by his support and we look forward to learning from Dr Linskey about TN treatments and also update us on the Gamma Knife /TN treatment.

### TNA Australia Young TN Forum

<http://www.facebook.com/tnaaustralia>

I am grateful to Lauren for setting up the Facebook site. This allows younger TN members a forum to discuss their social and work issues; and eliminate the helplessness and isolation.

When Lauren wrote to me I was impressed with her offer to share her personal experience. I felt that she would be perfect to offer young folks the support and be able to relate to their social or work issues. She also sounded like a level headed person that I could rely on to share accurate information besides support. Misinformed or misrepresentation of facts could do more harm.

So thank you Lauren for making this communication available to the under 40's

### Canberra Support Group Meeting: 26th May at 1.30pm

Please make a note of the above date and time. Jan G. has invited my participation at the next meeting in the hope of reviving members' attendance. I'll be talking on Vitamin B12 and other alternatives. Please don't let me fly down the Hume Highway only to hear your apologies. ☺

~ Irene ~



### Witty Quotes

"The secret to staying young is to live honestly, eat slowly, and lie about your age." - Lucille Ball

"Anyone who stops learning is old, whether at twenty or eighty. Anyone who keeps learning stays young. The greatest thing in life is to keep your mind young." - Henry Ford

"We don't stop playing because we grow old; we grow old because we stop playing." - George Bernard Shaw

"Age is an issue of mind over matter. If you don't mind, it doesn't matter." - Mark Twain

"Forty is the old age of youth; fifty is the youth of old age." - Victor Hugo

"Life's tragedy is that we get old too soon and wise too late." - Benjamin Franklin

# Topical ophthalmic amethocaine alleviates trigeminal neuralgia pain

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**Aim:** To test the effectiveness of local instillation of ophthalmic solution of amethocaine in relieving the pain of TGN.

**Methods:** We performed an open-label prospective study in 40 consecutive currently treated patients suffering from TGN with a reported visual analog scale (VAS) >8 (severe pain). The patients received two drops of amethocaine 1% instilled on the cornea ipsilateral to the painful side. Pain score assessment using VAS was recorded pre- and post-treatment.

**Results:** A total of 32 (80%) patients reported a significant reduction in pain 10 minutes after drops instillation as compared with pre-treatment pain score. Pre-treatment VAS score was  $8.53 \pm 0.6$  as compared with  $4.78 \pm 1.83$  post-amethocaine treatments ( $P < 0.00001$ ).

**Conclusion:** Topical ophthalmic instillation of amethocaine 1% can be considered as an immediate effective method for pain paroxysm of TGN.

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## Introduction

Trigeminal neuralgia (TGN), also called “tic douloureux”,<sup>1</sup> is a neurological condition affecting the sensory division of the fifth cranial (trigeminal) nerve and characterized by recurrent episodes of severe, shock-like pain confined to the distribution of one or more of the nerve’s three major branches: the ophthalmic (V1), maxillary (V2), or mandibular (V3). Typically, excruciating, lancinating facial pain occurs following stimulation of specific trigger zones by movement or touch. The paroxysmal pain may be felt in the lips, gums, cheek, or chin.<sup>2</sup> TGN occurs in about 1 in 25,000 in the general population and is uncommon before the third decade of age.

Pharmacotherapy is at present the first-line treatment for TGN and includes analgesics, anticonvulsants, and antidepressants. Surgical treatment is reserved for refractory and long-lasting pain.

Amethocaine, a 4-(butylamino) benzoic acid 2-(dimethylamino) ethyl ester, is a potent surface local anesthetic that acts by blocking sensory nerve endings near the site of application. In ophthalmology, amethocaine hydrochloride is used to anesthetize the cornea during ophthalmological procedures. When tested before, in a double-blind, placebo-controlled study, Kondziolka et al found that a single application of an eye drop of amethocaine did not cause any statistically significant pain relief in patients with classical TGN.<sup>3</sup>

The aim of the present study was to further test the effectiveness of local instillation of ophthalmic solution of amethocaine 1% in relieving the pain of TGN.

## Material and methods

A total of 40 consecutive patients (M-17, F-23) previously diagnosed with TGN and attending our pain clinic from January 1, 2005 to June 1, 2007 were included in this prospective case study. The diagnosis was made according to International Association for the Study of Pain (IASP) criteria.

## Instillation method

Two drops of amethocaine 1% were instilled onto the cornea ipsilateral to the painful side. After instillation the eye was closed for 10 minutes and the patient remained for surveillance in the pain clinic for another 20 minutes. For the patients with no significant pain reduction a second eye instillation was performed 15 minutes after the initial instillation. Changes in the severity of pain and frequency of attacks were assessed using the student *t*-test for paired data.

## Results

When attending the pain clinic, all patients suffered from severe typical sharp and lancinating pain in one or more trigeminal nerve branch distributions, facial hyperesthesia, and a visual analog scale (VAS) score .8 (Table 1). The pain attacks occurred despite the fact that patients continued their previous medications, which included nonsteroidal anti-inflammatory agents, opioids, carbamazepine, amitriptyline, duloxetine, citalopram, gabapentin, and pregabalin.

The pain was either spontaneous or aggravated by a trigger factor. Sensory branches of the trigeminal nerve that were affected included V1 (23), V2 (26), and V3 (23). Pain distribution in two divisions of the nerve occurred in 16 cases, and in all three divisions in eight cases.

A total of 32 (80%) patients reported a significant reduction in pain 10 minutes after instillation of the drops as compared with pre-treatment pain score. Pre-treatment VAS score was  $8.48 \pm 0.64$  as compared with  $4.53 \pm 1.77$  post-amethocaine treatments ( $P$ , 0.0001) (Table1). The pain reduction was noted regardless of the trigeminal distribution of the symptoms. All the patients also reported a reduction in the frequency of attacks for the following 24 hours (reported by pain diary). There were no adverse events reported in our patients.

**Table 1** Patient demographics and pain reduction (mean  $\pm$  SD)

Patient ( N)	Age ( years)	Pain Duration (years)	Pain intensity VAS score	
			Pre	Post
40	$58 \pm 15$	$4.5 \pm 2.5$	$8.4 \pm 0.64$	$4.53 \pm 1.77^*$

Note: \* $P$ , 0.0001. Abbreviations: SD, standard deviation; VAS, visual analog scale.

## Discussion

The first description of TGN was attributed to John Fothergill in 1773 (Fothergill's disease). However, early descriptions can be found in Avicenna's writings in the 11th century.<sup>1</sup> The International Association of Pain defines TGN as a recurrent, usually unilateral, brief stabbing pain in the distribution of one or more branches of the fifth cranial nerve.<sup>2</sup>

Amethocaine hydrochloride is a local anesthetic used for minor conjunctival and corneal surgery and is especially useful for the alleviation of pain resulting from removal of foreign bodies from the eye. Our study demonstrated the effectiveness of the application of amethocaine ophthalmic drops in offering a quick relief of the excruciating pain of TGN attacks.

TGN may be idiopathic (classic) or secondary to multiple sclerosis or benign compression of the Gasserian ganglion (the sensory ganglion of the trigeminal nerve).<sup>4</sup> The sensory root of the trigeminal nerve expands into the trigeminal ganglion, which contains the cells of origin of the sensory fibers and from which the three divisions of the nerve arise; it supplies the face, teeth, mouth, and nasal cavity. In 1991, Zvon and Fichte discovered the possibility of using eye anesthetics (proparacaine) for TGN by accident. Zvon, who suffered from TGN, found that his pain vanished for over a year immediately after an eye anesthetic was applied (for corneal ulceration). They then tested the anesthetic on another TGN patient and achieved pain relief for over a month.<sup>5</sup> We should note that repeated use of eye anesthetics may cause toxic keratopathy and may also slow down the healing of eye wounds. Hence, it was recommended that eye anesthetics must be used with great care and that patients should be advised not to rub the eye for at least an hour. However, in our patients, we have not noticed any adverse effects.

Although the pathophysiology and precise etiology of TGN are unknown, both central and peripheral mechanisms have been proposed. Current evidence suggests focal demyelination as a result of vascular compression of the central axons of the trigeminal nerve to be the underlying cause of TGN.<sup>4</sup> It therefore seems that there are several possible theoretical explanations for the beneficial effect of amethocaine ophthalmic drops in relieving TGN pain attacks, eg, 1) peripheral (corneal) suppression of the trigger stimulus might influence the central perception of pain in all three divisions of the trigeminal nerve; 2) migration of local anesthetic from the cornea to the sphenopalatine ganglion; and 3) a central mechanism, with retrograde transport of local anesthetic to the Gasserian ganglion.

According to one suggested theory, the explanation is that peripheral injury or disease of the trigeminal nerve increases afferent firing in the nerve perhaps by ephaptic transmission between afferent unmyelinated axons and partially damaged myelinated axons, and the amethocaine may cease this aberrant activity.

Treatment objectives in the case of TGN are to eliminate pain, reduce the likelihood of recurrence, and prolong the time to recurrence by selectively destroying pain fibers without inducing excessive sensory loss, motor dysfunction, or other complications. Surgical treatment, including microvascular decompression; partial trigeminal rhizotomy; stereotactic radiosurgery; radiofrequency denervation; cryotherapy; or chemical denervation targeted to the root (rhizotomy), ganglion (gangliolysis), or branches of the trigeminal nerve, were suggested as potential means of treatment of TGN.<sup>6,7</sup>

However, these involve invasive procedures and substantial risk of complication as well as the need for extra expertise. Peripheral nerve blocks with high concentrations of local anesthetics were previously proved to be safe and useful in the treatment of TGN, leading to pain relief for weeks after an infraorbital block.<sup>8,9</sup> The treatment of TGN in general is hampered by poor-quality methodological trials.

Our experience presents the potential beneficial effect of topical ophthalmic amethocaine in alleviating TGN pain attacks. Due to the simplicity of this treatment, we suggest that it be considered as a first-line option to use for severe pain attacks in TGN. As the pain in TGN tends to be paroxysmal, treatment with ophthalmic amethocaine may be recommended as a rapid and effective therapeutic measure, especially when the patient cannot attend the pain clinic or is at home. Nevertheless, a prudent approach justifies more extensive randomized placebo-controlled trials with this treatment in order to further explore ideal dosage and possible side effects.

## Disclosure

No conflicts of interest were declared in relation to this paper.

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In view of the many members who are currently contemplating MVD – I hope this reprint of my 2003 experience – will offer you some insight – Irene.

August 2003: “ I had the privilege of watching 2 MVD performed by Dr. Dexter. I watched everything with great intent. Dr. Dexter was also kind enough to introduce me to the surrounding nerves and vessels. I am very grateful for this wonderful impressive experience. I saw, as in both cases – “that with the exposure done correctly, there was no need for an endoscope.” (quote Dr. PJ ) We were able to examine the whole length of the trigeminal nerve all the way to the brain stem. ALL was visible.

In the first MVD, there were 3 compressions, the Superior Cerebellar Artery, (SCA) the Basilar Artery and (I think ) the Posterior Inferior Artery. At each compression Dr. Dexter cut the arachnoid and freed the vessel. Then he lifted the vascular loop and rotated it away from the nerve (he described rotating the loop like flipping a bucket handle.) With great patience and care he placed rolled up Teflon between the vessel and the nerve. (each Teflon was rolled such that it was thicker in the centre.) These Teflon were stacked to form a “column” that will keep the vessel away from the nerve.

In the second MVD – it was amazing – her head was full of veins. I watched as Dr Dexter carefully and precisely cut away the arachnoid and moved the veins aside and even cut them. She had an arterial loop, (I think it was also the SCA) and a vein pressing on the nerve. The loop was carefully lifted and rotated, and Teflon were also placed in between the nerve and the vessel. Dr Dexter also mentioned that care was taken not to kink the vessel during rotation. The vein was freed, coagulated and cut.

The most boring bit was waiting while Dr Dexter sawed the hole in the skull - about 15 minutes of yawns! That was only because I could not get near enough to see. ☺

Once the bone was removed, the mastoid air cells were waxed ( I think he said to stop the cerebrospinal fluid (CSF) flowing out ), he then cut through the dura and when he had opened up the dura - Dr Dexter pointed out the bit of cerebellum protruding from the hole. After the cerebellum had sunk away from the opening, the surgeon called for the microscope and in we went.

On entering we encountered the Vestibulocochlear (8th) nerve and Facial (7th) nerve. It was clear why auditory monitoring is essential - we do get very close to it. The facial nerve was also monitored and each time we were near it, the signals sounded like someone banging heavily on the door.

Not far off was the CN V ( trigeminal nerve ) When he was decompressing the vascular loop at the brain stem, Dr Dexter pointed out the Meckel’s cave (it did look like a cave) and the Portio major and Portio minor. ( The root of CN V is divided into two parts: portio major and minor. Major is the sensory part and minor is the motor part.)

When Dr Dexter was satisfied that all vessels were taken care of, we exited the brain. Upon leaving, he waxed the air holes again, used bone cement to plug the hole and a titanium strip to hold it and the skin was stitched back.

I marvelled at the patience, the care and the gentleness exercised by Dr Dexter. Exploring for the offending vessel/s was a real buzz. I could watch live MVD all day. IT WAS AWESOME!”

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At every TNA Conference that I have attended in the US, experts like Dr Peter Jannetta, Dr Kim Burchiel, and many others emphasized the importance of having your chosen surgical treatment performed by a neurosurgeon who is well experienced in the procedure. **According to Dr P. Jannetta - an experienced neurosurgeon is one who does 30 – 50 (ops) a year.**

**Past Notes on TN Treatment : things you should not forget.**

Not all face pain is trigeminal neuralgia.

Diagnosis! Diagnosis! Diagnosis!

Take a drug holiday – evidence that the drug works better.

Hi Irene, Here at last is a copy of my own experience with MVD. It is my experience only, but it may help others. I am aware that everyone recovers at different rates so I have tried not to be too specific. As a registered nurse, I am aware of my responsibility and duty of care, so I have tried not to give information that may cause medical problems.

For 3 years I suffered from Right side Trigeminal Neuralgia, with only moderate relief from Lyrica. A high resolution MRA at Cabrini Hospital showed compression of the Right Trigeminal Nerve. In May this year I was operated on by Neurosurgeon Mr Andrew Danks at Monash Medical Centre. I am now pain free and recovering well from surgery.

Being a Registered Nurse it was particularly interesting for me to experience surgery and hospital from a patient's perspective. My preparation plan and recovery experience may be of help to others who are about to have an MVD or who may be unsure or perhaps fearful of this procedure.

Please remember that this is my experience only.

### **PREPARATION FOR SURGERY - PREPARE, STAY WELL AND BE POSITIVE**

1. Organise support for a 4-6 weeks recovery period.
2. Compile 'THE LIST' of tasks that you will need help with eg, Housework, Ironing, Bending to Dryer / Washing Machine, Gardening, Shopping -suggest add Cooking! Recruit shoppers to stock pantry and freezer.
3. Ensure carers understand their role and together, read through 'THE LIST' and delegate.
4. Stay fit and healthy. Keep moving, alternate rest and activity. Walk daily, with company if affected by medication. Rest. Power Nap - 20 minutes in afternoon. A good night sleep is important too.
5. Deep breathing exercises 5 times, 3-4 times a day.
6. Eat healthy food.
7. Maintain a positive attitude. Be grateful. Not everyone can have an MVD and this opportunity to be pain free.

### **POST MVD - RECOVERY**

#### **DAY OF SURGERY**

- Tried not to dwell on surgery or MVD statistics but rather on THIS IS THE LAST DAY OF TN PAIN.
- Awake in recovery and quickly checked TN trigger points, NO TN PAIN - A SUCCESSFUL MVD.
- Back in High Dependency ward. Mild headache and pain around incision. Pain relief good and offered regularly. Relaxed, comfortable and sleepy during frequent nursing observations.

#### **FIRST 4-5 DAYS POST OPERATION - HOSPITAL**

- Mild pain around incision with ear and neck tenderness managed well by oral pain medication.
- Surgical discomfort is minimal in comparison to previous TN pain.
- Light headed. Sitting out of bed, short walks around hospital ward. Independent with Personal Care.
- Eating everything with fibre as pain relievers can be constipating!
- Able to read, and solve sudokus. So all systems go!

#### **FIRST 4 WEEKS POST OPERATION**

WEEK 1 AND 2 are the most challenging and carers are needed.

- Be patient. Recovery not only from surgery, pain relievers and the anticonvulsants that will need to be reduced over the next 2 weeks, but also from the months of debilitating TN pain.
- Manage surgical pain as instructed.

- Sleep may be more comfortable on the opposite side to incision with 2-3 pillows. May need pain relief during night in first week or two.
- Feeling light headed, tiredness, poor concentration, sleepiness and low noise tolerance can be exhausting.
- As there is no longer obvious TN facial pain, it is easy for carers and visitors to forget that you have had neurosurgery.
- Gently remind them and show 'THE LIST'. Carer may need to restrict number of visitors and calls.
- Rest. A short sleep in the afternoon may be needed and you can be tired by the end of the day.
- Move around the house carefully and start short walks with a carer.
- Increase length of walks and outings with a carer. Go slowly with outings. It is easy to plan visits or activities when resting at home but it may be difficult to tolerate when put in to action.
- Appointment for removal of Staples and being able to wash hair is a positive first achievement.

#### WEEK 3 AND 4

- Feeling better every day. Anticonvulsant medication and pain relief medication ceased. Less tired and tolerating increased daily activity and outings.
- Able to stay awake all day
- 4 week Post Op Appointment with Neurosurgeon.
- Permission given to drive, short distances, familiar routes, off peak in daylight with a carer.
- No Bungy Jumping!

#### WEEK 5

- Starting to have more energy and confidence. Concentration improving.
- First car drive - Sunday morning is a safe time - take someone with you.

#### WEEK 6 and 7

- Getting on with things. Progressing toward Pre Trigeminal Neuralgia wellness and routine.
- First solo drive. Energetic, active, walking ½ hour every day. Planning the next stage of pain free life.
- Extremely grateful and making the most of being pain and medication free.



"ANY OTHER NAGGING PAINS?"

## Support Group Meeting Reports

### Brisbane Support Group

11 Feb 2012

30 Ridley Rd Bridgeman Downs

Present: Leonie G, Margaret and Colin B, Neil F, Jeff and Lorraine B, John and Marie, Sue R.

Apologies: Tony M.

**Tony M:** - Tony sent his apologies for this meeting as he was away at a wedding. He informed me he has been good lately and as a result was well enough to be able to go away on this trip.

**Corry G:** Leonie's Mum Corry has been better but is still holding in there. She is currently using the slow release morphine patches as a way of controlling the pain and continues to get B12 injections on a regular basis. She is determined to continue to do the things she loves to do though and not let this beast stop her trips away with Rod (Dad).

**Sue R:** - Was very interested to know what people meant when they described how they were feeling. For example, when someone says they have been good lately, what exactly does good mean and how can that be compared to someone else who also says they are good? It can be a hard thing to quantify as everyone experiences their personal pain differently and everyone has different levels of tolerance. This started an interesting discussion. Sue mentioned that she has found a combination of Lyrica and Tegretol work for her as the Lyrica makes the pain shorter and the Tegretol dampens it down. There is still a constant pain despite this.

**Lorraine B:** The senar treatment continues to work and she had her last treatment in November. She has had no shocks since then. Lorraine pain is herpetic, meaning it is from virus infection and she cannot take Tegretol due to liver problems, nor Lyrica as it gives her a rash.

**Margaret B:** Has contemplated having an operation to treat her TN for the third time since 1996. She is worried about an up coming dental visit and is currently increasing her Tegretol to help cope with the probable pain that will result. She also has been advised to take 3 Panadol before her visit. TN often makes her feel insecure as she never knows when it will hit next. Stress always seems to play a role in it getting worse. She has been taking Lecithin and has noticed small wiggles/fuzziness when she does not take it.

**Neil F:** Has been great. He continues to exercise and take Lecithin, flax meal (linseed oil), oral B12, magnesium and drinks lots of water. He believed moderation in life helps keep it controlled.

**Marie:** Has had no pain since the last meeting...it has been great. She tried Trileptol just before Christmas but it did not work so she is on the Tegretol again. She would like to try it again though and this time not go cold turkey from the Tegretol but do it slowly and see if this helps. She has noticed that she does get a tiny twinge if she goes 12 hours without medication. Marie does not currently take B12 but will probably start taking it again soon.

Everyone at the meeting was interested to find out what was the results of Irene's Soy trials.

Gold coin donations: \$20.00

Next Meeting: Saturday 14<sup>th</sup> of April 2012.

My apologies for the shortness and lack of detail in the notes from this meeting; 3.5year old Eamonn attended the meeting with me and although he behaved wonderfully and kept occupied and quiet, I was unable to take detailed notes while keeping half an eye on him and conducting the meeting. My apologies also if some of the detail is incorrect.

~ Leonie ~

# Townsville Support Group

Saturday February 18 2012

Present: Sera A, Peter A, Joy K, Roy W, Nancy W, Jill S, Mary C, Sue M.

General chatter about old neurologist retiring and 4 new ones coming – one will be going into private practice and the others will be working at the hospital.

We also discussed Sera's difficulties with Myesthenia Gravis as well as having TN. Myesthenia Gravis crept up on her very slowly and without warning. Roy has Sjogren's Syndrome as well as Trigeminal Sensory Neuropathy

**Sera:** Introduced Mary and Jill to the new couple and welcomed Roy and his wife to the meeting and explained that the meeting helps us to cope. Her pain comes and goes but tends to knock her at night.

**Roy** has Trigeminal sensory neuropathy and experience a mixture of pain and numbness. He finds it difficult to talk. His pain varies from pins and needles stabbing him to numbness in upper lip and lower lip, tongue down to jawbone. Brushing teeth can be like using a grinder. Roy's MRI also shows a little dot on the trigeminal nerve. They saw the ad. for the meeting on TV.

**Sera** said that the support meeting was advertised on local TV, local newspaper, and flyers in chemist.

**Nancy** said she thought that Roy was having a stroke to begin with. Nancy says that the hair and the lashes grow more quickly on the side with the Trigeminal Sensory Neuropathy, and his eye droops and talking is difficult.

**Jill:** Pain has been dreadful, so bad that she couldn't cope. She had been taking more and more Lyrica. Dr put her on strong Dylantin instead and she wasn't allowed to drive for a little while.,,She said that no-one knows about it and we all agreed that it wasn't visible. Jill also feels that TN can run in families.

**Mary:** Some of Roy's symptoms seem similar to hers. Mary's pain starts in behind the ear and into the scalp, eye can be blurry and teary. However Mary believes the cut on her jaw contributed to her pain.

**Sue** said that sometimes hers was like that as well. But her pain is still under control most of the time. It breaks through during stressful times or when there is too much time lapsed between the morning and evening doses.

**Sue** then handed out and explained 2 sessions from the Conference - Dental Hygiene and TN and Irene's session on the Capsaicin creams, compounding and B12. Next time she will go over some of the others.

Jill read one of the poems from the Conference Book. Sera got Jill to read an old poem from the newsletter.

In our general discussion we talked about having the shakes - Sera keeps dropping cups of coffee. Sera wants to thank Peter for looking after her.

We also discussed alternative treatments such as Pain Shields ( please refer to the February Newsletter) and Acupuncture.

Sera then thanked everyone for coming and we ended meeting with afternoon tea.

Next meeting TBA depending on date of Sue's new grandchild in Townsville as that is the next time she will be in.

*~Sue & Sera~*

*Have been praying for you since I learned of your MG, am very glad you are getting stronger –Irene.*

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# Sydney Support Group

Toongabbie Public School

3rd March 2012

Attendance: Jeanette & Henry B, Rose & Peter H, Jan M, Anne & Laurie P, Bertha & Ross M, Ken & Marj F, Douglas M, Frank M, Kim K, Kim S

Apologies: Irene W, Beryl T, Stewart & Gundel, Elizabeth & Lloyd

**Beryl** sends her apology. She has had acupuncture once a week for 3 months and is moving to once a fortnight. She is changing from B12 to injections. She is currently drug free and has a little bit of pain.

**Elizabeth** had a fall recently but her TN is OK. Lloyd has pneumonia. We send our love and best wishes to them all.

**Irene** was unable to get to the meeting as she was marooned on the hills with both the Nth Richmond and the Windsor bridge closed due to the rising Hawkesbury River.

Today we welcomed new member Bertha and her husband Ross. We first spent some time checking up on all our members before hearing Bertha's story.

Ann is happy to report she is still going fine.

**Jeanette** said her TN is fine but she has had a recent fall while vacuuming and has some war wounds!

**Jan** is still fine since her MVD 4 years ago. She is starting to get more feeling in her face but the dryness in her eye bothers her.

**Peter** has post herpetic neuralgia and there is no changes since last month.

**Rose** has been having some abdominal problems which are yet to be diagnosed. We hope you get an answer soon.

**Frank** has been suffering from some breathing difficulties and is using Ventolin. Jan suggested investigating Sleep Apnoea as her husband had similar problems and has found the mask very helpful.

Frank reported that **Norma** is much the same. She is getting lots of "tics" – apparently more than he sees according to Norma, but she doesn't want to go back on Tegretol.

**Marj** has recently had a tooth removed. She increased her medication in anticipation and then dropped it slowly each fortnight and everything was ok. She still gets mild attacks and uses a heat pack for relief. She currently takes 600mg Tegretol and 200mg Epilim. Changes in the weather seem to affect her.

Marj has recently had a rash on her legs and wondered if it was from the B12. No one else has had this experience. She will trial it again to see if it was the cause.

**Kim S** is still getting the unusual sensations in the face which seem to be triggered by similar things to TN attacks. They feel like the very mild beginnings of TN. She is taking B12 and Magnesium, and also has the dry eye like Jan.

**Kim K** has been on 300mg Tegretol for the past 2 years. Her pain has recently worsened so she increased to 600 and is now on 800mg. Still has lots of burning pain. She is now seeing an acupuncturist. The acupuncturist has advised not to drop the medication until she achieves a pain free status.

**Doug M** feels terrible at the moment. He has a complex combination of problems. ( I hope I get this right Doug –my apologies for any errors) He has scars on his spinal cord from an accident in the 80's and also has TN. He is also wondering if he has developed Anaesthesia Dolorosa.

He has two Motor Cortex Stimulators. They help his legs but he is losing feeling in his feet and this loss of feeling is moving up his legs. He is not sure if he has shoes on today!

Doug finds a warm pack on his face gives him a little relief. He has tried many different treatments – acupuncture, tens machine, massages. We were amazed at his positive attitude despite all his problems. I asked him how he copes and stays so positive.

Doug said he is a workaholic and finds the distraction very good. He knows the stimulators help because he feels the difference when they are off. He has had some damage from a stroke but is not sure whether this or the TN has caused more problems.

Doug worked as a Biomedical Engineer and now does some public speaking about the work he has done and how he copes with all his problems. He certainly had us entertained this afternoon.

Peter and Doug also told us some funny stories about setting off the alarms in the supermarkets and how they have had to develop relationships with the staff in their local shops so they don't get interrogated every time.

We have asked Doug to give us his presentation on his Medical Invention at our next meeting.

Coincidentally he won an award for inventing the mask that is used in Radiotherapy. Our new member Bertha used this when she underwent radiosurgery.

Bertha has had Right side pain since 2008. She went down the all too familiar path of having teeth removed before being diagnosed with TN by the GP. She started on Tegretol and then had an MVD in Dec 2008 which gave her only minimal relief. She is now taking Tegretol, Neurontin, Epilim, Endep and another antidepressant. She has also tried acupuncture and had radiation treatment in 2011 which also had no effect. She describes her pain as sharp and she has some numbness and tingling around her lip. She is currently seeing Prof Aggarwal.

We then shared our recipes and ideas for getting some nutritious food when we are having trouble eating. Jeanette brought along some fat free, sugar free, gluten free marshmallows for us to try. "Sugarless" brand available from some chemists.

Ken and Marj –Ken chops things up very small for Marj. He brought a delicious recipe for Asian Lamb Shanks

Peter and Rose brought along a recipe for Char Grilled Mediterranean Salad

Doug likes to put apple puree in raisin toast in the sandwich maker for a yummy sweet treat.

Jeanette remembers relying on Weetbix a lot.

Anne brought a recipe for gluten free Roasted Vegetable and Goats Cheese Quiche.

Kim S had some brochures from a dietitian which gave lots of suggestions for really nutritious meals like soups, smoothies, high protein shakes. By adding a scoop of skim milk powder you can get some additional nutrition.

We also discussed how your jaw needs to work a bit. Too much pureed food may have a negative effect on the way the body works. It was also noted that it is sometimes possible to work through an initial attack when you first start eating and then you may get a window of opportunity to eat without pain.

Kim K reminded us that we have a guest speaker on Bowen Therapy in July. We will also have Doug's talk on his Inventions in May.

Thanks to everyone for the yummy afternoon tea and assisting to pack up the hall and of course, Henry and Jeanette for the raffles.

*~ Kim K & Kim S ~*

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# SUNSHINE COAST SUPPORT GROUP.

Kawana Library, Nanyima Street, Buddina.

Saturday 10<sup>th</sup> March 12

**Present:** Jill Z, Jill L, June H, Ellen B, Sherryl M, Jean W, Jean B, Dorrie H, Trixie B, Josef A & Dawn S.

**Apologies:** Max H & Teresa M.

## General business:

- Lauren Smith has the face book site up and running. [www.facebook.com/pages/TNA-Australia](http://www.facebook.com/pages/TNA-Australia). Anyone interested can check it out. Many thanks to Lauren for a job well done.
- Phone call of thanks from Peter & Pearl. They were thrilled to the back teeth that they had been thought of in that way.
- Correction from the last report. Ellen's operation was at the Brisbane Private Hospital.

\* Welcome to June H & thank-you Ellen for bring her along to the meeting.

## Reports:

**Josef:** Spasmodic pain has returned. Breathing deeply an exhaling hard helps. Joseph is only taking B12 and acidophilus.

**Jean B:** Not much to say. Her pain is still present- coping well with it. Her medications are as follows: 600mg per day Gabapentin with Capsaicin cream 3 times per day. Jean is now able to sleep through the night.

**Ellen:** After her MVD, Ellen isn't taking any medications, no pain and is doing very well.

**Dawn:** Gone back onto Tegretol taking (200gX2pd slow release) has come off Endep. Pain is still getting worse at times. Tried Capsaicin cream and she has found that it is of some help. Has a terrible rash on her hands and sometimes on other areas- unsure of the cause.

**Jill L:** Going to see Dr. Dexter on the 22<sup>nd</sup> March. Feeling a little anxious about the MRI and having to keep still for an extended amount of time. Jill was hospitalized with pain recently. Tegretol isn't successful. It is better after finding a new way to swallow full tablets previously tried a little custard. Dr. advised trying Tegretol & Gabapentin. Then said not to? Oxycontin doesn't seem to help. Jill is having trouble eating, was advised to go the pharmacist and try Sustagen (hospital strength) and possible meal supplements. Jill is going to contact Dr. Dexter's office to advise of her anxiety, so the MRI technicians are ready for her.

**June:** Left side pain. June is having her MVD on the 11<sup>th</sup> May. Her first attack was in 1997- in the beginning the pain was frequent whereas now it is constant. At the moment she is taking Gabapentin 600 2xd, Endone if needed. Good luck with everything.

**Jill Z:** Found reading "Striking Back" most interesting. Using Neuroveen drops into her mouth for neuropathic pain. Having problems with burning mouth and is starting to get pain in her mouth. Her Osteopath has helped with jaw adjustments. Trying a new dentist. Using Endep. Still able to sleep Ok and feeling much happier and no longer depressed. If you try chewing sugar free gum it may help with the dry mouth.

**Trixie:** After her MVD she hasn't had any pain for 2 years. Feeling wonderful, looking great.

**Dorrie:** Has a rash on her back from Lyrica. Taking Gabatene 100 mg X2. Not holding her pain as well as Lyrica. She also takes Tegretol 1200mg daily. Asked if the rash was from Tegretol? It would be advisable to check it out further.

**Sheryl:** Cold wind in Sydney stirred things in her face. Only getting occasional twinge. Sheryl feels she probably needs another cranial/cervical adjustment.

**JeanW:** All fine.

**Josef** gave a demonstration on the process that he uses. Josef uses universal energy to align the chakras in ones' body. This helps the body repair itself. A demonstration was done on Jill L where Josef attempted to relieve some of her pain. Afterwards, Jill certainly looked relaxed and we hope that she gained some relief from the experience. Thanks so much Josef.

Next meeting: **Saturday 19<sup>th</sup> March, 1pm.**

Close of meeting followed by afternoon tea. The spread looked and tasted fantastic. Thanks for all the effort everybody and appreciations to Sheryl for taking report.

#### **Positions vacant:**

**\*Beverage superintendent.** Afternoon tea.

**\*Direction coordinator.** Placement of directional signs & collection of said signs.

**\*Personal Assistant.** Scribing meeting reports and emailing said reports to Irene.

**\*Public relations.** Door greeter; sign in sheet and name/tag coordinator.

**\*Advertising.** Meeting dates to be forwarded to newspapers, TV and radio.

I guarantee that if you help someone else (Me) you will feel great afterwards. - *Jean W*

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### **Correspondence Corner**

**Lois W:** No joy yet with the date for op.- don't know just where I am in the 1 to 365 day waiting list, I only received a letter from Hosp. confirming that I was on the waiting list. I saw the Dr. on the 5th Dec. and they hand delivered my details to them on the 12th Dec. After a really bad stretch I was lucky last week and had six days straight without pain, however today it's back. Just have to grit my teeth and do my best.

**Ben H (Newcastle):** Unfortunately I suffered a major heart attack st1March and a stent was inserted to stabilise me for the time being. I was discharged from hospital yesterday. Next Tuesday I see the surgeon and hopefully he will be able to advise the date for the by-pass operation I need. The wait is to let my heart recover enough (hopefully )aftr the stent op so they can do this by-pass (at least a triple at this stage). I'm resting at the moment but apart from feeling tired think I'm ok.

**Kate M:** I have been talking to Irene about the support group and general information. I have TN and am getting the MVD procedure tomorrow. Regardless of what happens I'd like to be a member of the TNA. I have deposited \$25 for my membership, \$10 for my Mum to be a member and a \$15 gift, because the information that Irene and Evelyn have provided me with has been amazing over the past week. I now feel very prepared for tomorrow.

**Beverly L:** This trigeminal numbness started after I had had my teeth cleaned on 10th January with an ultrasonic cleaner. I have heard that this can trigger the complaint and it fits in to the time line when it started. It did start on one branch – the central one and slowly spread up my face to my eyebrow/forehead and into my hairline and front scalp. I then noticed my chin was numb as well, but that was over a few weeks, I think. My pain is more of an ache, but sometimes more in the joint, but nothing like what has been described in your newsletters, suffered by many others.

**Beware the ultrasonic cleaner!**

## 2012 Meeting Dates

<u>State</u>	<u>Group</u>	<u>Date &amp; Time</u>	<u>Venue</u>	<u>Group Leader/s</u>
ACT	Canberra	26 <sup>th</sup> May 10.30am- 2.30pm	Barbara Byrne Room Labour Club, Belconnen	Jan Goleby ☎ 02 6254 6640
NSW	Sydney	5 <sup>th</sup> May 1:30 – 4:00 pm	Toongabbie Public School Cnr Fitzwilliam & Binalong Roads	Kim Koh ☎ 02 97431279 Kim Smith
	Sydney CBD	2 <sup>nd</sup> June 10am –12:30pm	St. James Parish Hall, Level ONE, 169 Phillip St. Sydney CBD	Irene Wood ☎ 0413 363 143
QLD	Brisbane	14 <sup>th</sup> April 1.30-4.00pm	30 Ridley Road BRIDGEMAN DOWN	Leonie Gall ☎ 0407 55 44 07 Tony MacPherson ☎ 07 3822 2286
	Sunshine Coast	19 <sup>th</sup> March 1:00 PM	Kawana Library, Nanyima Street, Buddina	Jean Williams ☎ 07 54911978
	Townsville	TBA 1.30 – 4:00pm	Carville Senior's Villa 35 – 37 Diprose St PIMLICO	Sue Macey; Sera Ansell ☎ 07 47516415
S.A	Adelaide	27 <sup>th</sup> May 2:00 – 4:00 pm	Burnside Town Hall Civic Centre Cnr Portrush/Greenhill Rd	Graham/ Liz Boyer ☎ 08 8392 2781
TAS	Hobart	TBA 2:00 – 4:00 pm	Glenorchy Library Enter via Barry and Cadell Streets	Helen Tyzack ☎ 03 6245 0429 Ros Wilkinson ☎ 03 6234 7989
VIC	Melbourne	14 <sup>th</sup> April 1.30 – 4:00pm	"Ringwood Room" Ringwood Library, RINGWOOD	Evelyn Diradji ☎ 03 9802 6034

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