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.

OCTOBER 2010

My Face

A toothache that isn't, teeth are all sound,
by X-rays or scans the pain can't be found.
All that remains is the vein out of place
pressing on the nerve that leads to my face.

Just wanting a kiss, but getting instead
electric shock, stabbing, stilling my head.
Unable to eat, talk or to drink
becomes impossible even to think.

The problem inside a head too stressed.
Yet more pills taken; how much will arrest
the sensitive trigger? More dulls the pain,
but sleep and nausea swamping the brain.

Busy at work, I try to remember
the task given me by a team member.
Struggling and frustrated, I reach for a hand
But finding instead, retirement unplanned.

Kerry Graf
Canberra.

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A brief account of my attendance at TNA USA 10th National Conference and the IASP 13th World Congress on Pain in Montreal.

No rest for the wicked. A meeting was already scheduled for Friday morning with Prof. Joanna Zak, Dr. Barbara Yawn (Co-Director of the Rochester Epidemiology Project), all Chairpersons of the 3 TN Association and staffs. We met to discuss doing a study on the epidemiology of TN, and worked on refining the questionnaire. We then did a trial run of the survey questionnaire during the conference the next morning, and judging from the response more work needs to be done on the questionnaire, as we want to get it right this time. All data collected would give precious insight into TN and neuropathic facial pain. Once this questionnaire is fine -tuned and is distributed I expect every TNA Aus member to get behind it and fill out the questionnaire. This would be a major USA, UK and AUS effort.

As Prof. Zak, Claire and myself were enroute to Montreal, the President's Pin event was scheduled straight after Joanna's talk to enable us to get away in time for our flight. I was especially delighted to see members of MAB attending and supporting the Pin event.
Yes, I do have the President's Pin safely in my keeping. I have promised Claire that I would wear it to support group meetings; to wear it with pride and in good health, and not to lose it! ☺

The International Association for the Study of Pain (IASP) Congress is as always rich with information and provided plenty to learn. My only problem is after 3 weeks on the road, I come home to try and decipher my handwriting - a major task!

However, there is one talk I would like to first share with you and look forward to your response.
Below are my notes made from her talk - any error is strictly mine.

From the Descending Pain Modulation to Obesity via the Medullary Raphe - Peggy Mason.

" My real goal is to convince you that taking an evolutionary and ecological perspective on pain modulation can give us valuable insights and that some of those valuable insights may even have clinical relevance."

As an introduction to the descending pain pathway, she quoted many works that have described and charted the pathway for descending pain modulation. This pathway starts in the midbrain, in the periaqueductal gray. Stimulation here produces a profound analgesia; and that the analgesia is affected onto cells in spinal and medullary dorsal horns. The analgesia system descends to change the response to incoming nociceptive information at the site. It does not ascend to modulate nociceptive in the thalamus or cortex. But cells in the midbrain do not go directly to the dorsal horns, they reach the dorsal horns via relay station in the medullary raphe; and this includes the Raphe magnus – also known as the rostral ventromedial medulla.

For the purpose of her talk, she focused on the role of the neurons in the raphe magnus in descending pain modulation and analgesia. The cellular mechanisms, as proposed by Howard Fields' cell model in 1983, basically described 2 different types of cells : the Off Cells and the On Cells.
Off Cells - are cells that are inhibited by pain, they are activated by analgesic doses of opioids;
On Cells - have the opposite characteristics, they are excited by pain and are inhibited by opioids.
As Howard Fields found in 1983 and have been consistently proven " If you give an analgesic dose of an opioid the On Cells will be inhibited, they will be silent, while Off Cells will fire continuously."

Mason stated that her interest tended more towards the animal behaviour. There are thousands of literature on wild animals, but the number of times you see an injured animal that survives to exist in chronic pain is zero! An animal that is injured dies; or it gets better. There is no chronic pain situation. Chronic pain therefore does not play a large influence on evolution. It is also very difficult to demonstrate that an animal can release a level of endogenous opioid that is analgesic.

So, with there being no chronic pain state and rarely enough endogenous opioid to produce analgesia, what then is this system doing for a regular animal living a regular life?
To answer this, they looked for situations where the cells look like they had just got a shot of morphine, ie: the Off Cells are active, and the On Cells are inactive.

They found 3 situations - where the Off Cells were active and the On Cells were inactive:

1. Slow Wave Sleep
2. Micturition *(urinating*)
3. Eating.

Her studies showed that during the contraction of the bladder muscle that pumps out urine there is a burst of activity; and these action potentials occurred during the voiding episode - Off Cells are excited and On cells are inhibited during micturition. The response to a noxious stimulus is greatly attenuated during wetting.

Also when the animal is eating, the On Cell activity is nil. When the rat was nibbling on paper, the cell activity was on and off, in correlation to that nibbling. Likewise, withdrawal is also suppressed during voluntary eating. But **sensory suppression** has nothing to do with appetite or calories; it **accompanies the actual ingestion of food.**

Majority of the time the rat would withdrawal and turn around and lick its hind paw that was heated. What they found was that it essentially did not happen. They gave the rats 934 chop chips (rats love choc chips) and less than 10 times did the animals decide to drop the chip and turn around and to lick its paw.

"Under the normal situation Raphe is providing a pro-nociceptive, a pro pain facilitatory drive on to the dorsal horn in the presence of a noxious stimulus. Raphe comes down and facilitates the response and the opioid disable the facilitation coming from the Raphe. This means that Raphe is dealing with an analgesia for a short amount of time and only in the situation when the pain stimulus comes in."

Now, you might ask why this is interesting? Well, I recall TN patients saying that if they persist with eating their dinner, their pain stops and they can then eat the rest of their dinner without (much) pain. Perhaps the above explains why.
My next question then is **"Does that mean that when TN patients urinate (or poo) their TN pain stops too?** I am very curious. Could you please take note and let me know. Just yes the pain stopped, or no, it didn't. I don't need to know other details. ☺ Also Professor Mason is interested in your response.

TNA Australia Conference 2011. September 2 - 4

I take this opportunity to remind you that our conference is less than a year. Have you made any commitment towards attending? Work has begun on our end.

Irene.

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Psychology of Pain

Extract for Assessment & Management of Orofacial Pain: J Zakrzewska, S Harrison, (Elsevier Press.)

Strategies for coping with pain

At the risk of stating the obvious, coping with pain, and in particular, Trigeminal Neuralgia pain is one of the more difficult tasks in life. Pain is often conceptualised as a 'warning signal' alerting us to the fact that there is something wrong in our bodies. Severe pain therefore is an alert of something very wrong, which needs urgent attention in order to be put right. This is of some value when the pain is telling us we have a broken limb, or have appendicitis, or are about to give birth. We have some idea of how to use the information that the pain is giving us in these situations – we know what to do, or at least what we should be doing.

Chronic neuropathic pain such as TN defy such rational explanations – what is the pain telling us to do in these cases? This urgent, insistent message from our bodies alerting us to the fact that something is very wrong does not convey the same information about how to respond. After all, other than taking medication, there does not appear to be very much that we can do to stop the pain. One of the most upsetting aspects of chronic pain can be the sense of helplessness that accompanies it. You feel as though you must do something to make it better, but there is no obvious resolution to the pain that you can apply.

One of the ways in which you might think about changing your approach to the pain is to think of a flare-up not as a disaster but as a challenge. How are you going to respond to this – with an increase in anxiety and frustration and distress, which will inevitably worsen the pain; or with as much calmness and rational thought as you can muster? Coping well with a flare-up of pain is a bit like riding a wave; you cannot stop it but you can stay on your feet and flow along with it until it eventually subsides (which it *always* does, even though it often does not feel like it at the time).

Having made a decision that this flare-up is a challenge that you are going to attempt to meet, the following strategies can be useful. They are not presented in any particular order; you can try them in any sequence that you like. The main idea is to keep yourself occupied by moving from one strategy to another, alternating between rest and activity. You need to be aware that overdoing things when you are in pain is tiring and will reduce your resources for coping,, whereas doing very little at this these times will not leave your brain sufficiently distracted and you become at risk on focusing more on your discomfort.

- Do not panic – try to think of the pain as a challenge and you are going to experiment with different ways of coping with it.
- Prioritise: Coping with this pain is going to mean that you do not necessarily do all the things you were planning to do in the next hour or two. What can you leave until later, or ask someone else to do, or cancel completely?
- Communication: Although coping with pain is a personal event, it may be useful to let those close to you know what is happening at this time. This is especially important if you prefer to be alone, or if you tend to become quieter so that you can concentrate on dealing with the pain. It is easy to misinterpret someone leaving the room or going quiet – family members may thing they have done something to upset you. Communicating about pain does not mean complaining about it; something like this can be useful "Listen, I am just going upstairs to manage this pain for an hour. You (family) keep doing what you are doing, I am OK but I just need to concentrate on this for a bit".
- Relaxation: (5 – 10 min.) Doing some deep, controlled breathing can help to keep you feeling reasonably calm and in control. There are many techniques for relaxation, from yoga to meditation to hypnosis. They all share a common element, which is that you are doing something quite active even though you may not be moving at all. Relaxation is not the same as doing nothing, you do have to concentrate. But be realistic – being in pain is about the least 'relaxing' state you can be in, and very few people are able to drift off into a completely comfortable state. Whenever the pain intrudes on your thoughts, just gently bring your mind back to your controlled, regular breathing. Your aim is to try and keep as calm as possible, rather than to go to sleep. Sleeping during the day can seriously interfere with your sleep at night, and that can compound the situation.
- Light Activity (10 – 15 min) Even though you are in pain, you should still attempt to do some non-vigorous activity. Things like watering the plants, paying a bill, simple cooking, polishing shoes, gentle ironing and so on. The activities must be physically and mentally undemanding, and you should not attempt to do them for any longer than about 15 minutes. However, you will discover that even when in a bad way with the pain, you can still achieve things that need doing – and that can bring some satisfaction.
- Rest: (any time up to 20 min). This is complete time out, where you do not need to concentrate on anything other than giving your body a chance to recoup some energy. You might lie down on

the bed or floor, or sit in a comfortable chair. Having a cup of tea, listening to music or watching TV can all be restful activities, but remember not to 'do nothing' for too long because the pain will begin to dominate your thinking if you are not sufficiently distracted.

- Gentle stretching (10 – 15 min) Pain can often result in increased muscle tension, which will then make the pain worse. Simple, gentle stretching of the neck, upper back, shoulders, arms and lower back can all help to keep you from getting too tight during a flare-up. Going for a slow, gentle walk can also be helpful. As long as you do the stretches slowly and gently and do not try to overstretch, you will not do yourself any harm
- Distraction (5 – 10 min). All of the activities above have a distracting element to them, but you might also try and divert your mind away from the pain as an activity in itself. Distraction requires concentration, so think of an activity in itself. Distraction requires concentration, so think of an activity that you get really absorbed in such as sewing, or model making, or painting. Have these activities at the ready so that you can just pick them up when the flare-up requires them. Talking to someone can also be excellent distraction – provided that you do not talk too much about the pain! You might say "I am in a pain flare-up at the moment. I'm OK, but I need you to take my mind off it for a while. Tell me what you did today/movie you saw/ holiday you are next going on etc". Try and involve yourself in the conversation as much as possible.
- Reflection and reinforcer: Once you have got through the flare-up, having tried out these various strategies, have a think about how it went. Did the pain last as long as it usually does? Did you feel more in control of the pain? Were you still able to achieve a few things, even though you were in pain? Is there anything that you could do differently next time – change the order in which you do things, do certain activities for longer or shorter, get partner/friend involved more? Whatever you decide, it is very important that you give yourself a 'reinforcer' for having tried to cope with the pain in this way. A reinforcer is a small treat that you give yourself for your own hard work in coping with pain, such as a magazine, pot plant, make-up, special food (chocolate!) or video. It is a small pat on the back that you give yourself for your efforts, because only you really know how tough it is to cope with the pain.
- Be creative and experiment with different ideas. Each flare-up gives you the opportunity of learning something more about the pain and something more about your capacity to cope with it, so good luck!

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HOW DENTAL CARE – GOOD & BAD, AFFECTS TN

Excerpted from TNALERT Spring 2001.

In a session on "Dental Care & Hygiene for TN Patients" Henry Gremillion DDS of the University of Florida College of Dentistry explored 3 major connections between TN and dental care:

1. When TN pain begins, a dentist is often the first health professional an individual turns to. Diagnosis is difficult because the head and neck share the same neurological circuitry, which means that different head and neck disorders often produce similar symptoms. In particular, pre-trigeminal neuralgia can mimic tooth pain. Pre-TN generally causes background aching with occasional lightning-like jolts of pain. A knowledgeable dentist can use a local anaesthetic to make a diagnosis: if pain relief from the injection lasts substantially longer than the effect of the local generally lasts, the patient may have pre-TN.
2. Dental treatment can cause TN by damaging the trigeminal nerve. In such cases the demyelination of the nerve takes place in a peripheral nerve area, rather than near the brain stem. There is evidence, that when a peripheral nerve is injured, it develops new sodium channels and thus becomes more sensitive. In a phenomenon almost like sunburn, it begins to fire in response to non-painful stimulation. In other parts of the body, damaged peripheral nerves usually recover, perhaps by remyelinating; we don't know why this doesn't happen with trauma induced TN.
   A number of dental procedures have the potential to damage the trigeminal nerve. Dr Gremillion believes that even the needle that delivers an injection of local anaesthetic can do it, damaging the nerve's myelin sheath or exacerbating a nerve injury that already exists. He recalled that when he was in dental school, he got an 'A' if the needle he wielded gave the patient a jolt of pain because the pain proved he had found the nerve. He now says that if a patient gets a jolt from the needle, the dentist should immediately pull the needle back.

3. Dental procedures can stimulate the trigeminal system and thus trigger or worsen the pain of TN. Dr Gremillion suggested a number of ways to prevent that from happening, but firstly he emphasized the importance of maintaining good dental hygiene. Many patients avoid going to the dentist, afraid the visit may worsen their pain. However, if their teeth decay due to neglect, that in itself can augment TN pain even as it makes future dental procedures necessary:
   - Know your pain cycle and schedule dental appointments during remissions, then use pre-emptive analgesia to reduce aggravation to the trigeminal nerve. Ask the dentist to work with your doctor and advise you on how to boost your TN medication, beginning a few days before the dental appointment.
   - You might increase the dosage of your usual drug (or start it again, if you have been of a drug holiday) or add a small dose of different medication. How much extra medication you need depends on the procedure you are having – a cleaning for example would require less.
   - In order to protect the trigeminal nerve for as long as possible, pre-emptive analgesia should also include a pain killer taken before the procedure and again afterwards before the local anaesthetic has worn off.
   - Other medications are worth considering; a nonsteriod anti-inflammatory to reduce any inflammation as well as pain.
   - To maximise your own comfort during the procedure, if you think it would help, bring a pillow from home.
   - Some people like to use laughing gas was well as local because the gas relaxes them. Steven B Graff-Radford, DDS of Cedars Mt Sinai Medical Centre in LA stated that local injections are better for TN patients than general anaesthesia because a local actually interrupts pain signals to the brain, whereas "all anaesthesia does is knock you out. Any time there is sensory input into the nervous system that increases TN pain".

HOME DENTAL CARE TIPS

For home care of teeth, Dr Gremillion has a number of suggestions:

1. Attend to your teeth at the time of day when your TN medication is most effective. If brushing is painful, you might use a topical anaesthetic beforehand. To reduce the chances of decay, he suggested applying a fluoride gel or using an antibacterial mouthwash.
2. Don't have your teeth whitened, either by a dentist or with a home-applied bleaching solution.
3. Avoid tartar control toothpaste which can irritate the gums.
4. Use a super soft toothbrush.
   (Some members report that using toothpaste designed for sensitive teeth has enabled them to brush without TN flaring up)

PREVENT TN FLARE-UPS AFTER DENTAL WORK

For a day or so before and after the procedure, increase the dose of any TN medications you're taking. Ask your dentist to use **Marcaine** without **Epinephrine** for the local anaesthetic. You may need to ask in advance because the average dentist doesn't keep this particular drug in stock. **Marcaine** is long-acting, so you're less likely to need multiple injections – each one producing pain signals. Epinephrine is a vasoconstrictor; added to a local anaesthetic it prevents blood flow from carrying away the anaesthetic and thus prolongs its numbing effect. However, **Epinephrine** can trigger nerve pain, so you're better off without it.

Ask the dentist to inject the local anaesthetic at a site as far away as possible from the trigger point for the TN pain.

The below poem was sent in by Hilary W. "I think you will enjoy it."

Irene: a parallel of the elephant and TN..?

THE BLIND MEN AND THE ELEPHANT

John Godfrey Saxe (1816-1887)

It was six men of Hindostan
To learning much inclined,
Who went to see the Elephant
(Though all of them were blind),
That each by observation
Might satisfy his mind.

The *First* approached the Elephant,
And happening to fall
Against his broad and sturdy side,
At once began to bawl:
"God bless me! but the Elephant
Is very like a wall!"

The *Second*, feeling of the tusk,
Cried, -"Ho! what have we here
So very round and smooth and sharp?
To me 'tis mighty clear
This wonder of an Elephant
Is very like a spear!"

The *Third* approached the animal,
And happening to take
The squirming trunk within his hands,
Thus boldly up and spake:
"I see," quoth he, "the Elephant
Is very like a snake!"

The *Fourth* reached out his eager hand,
And felt about the knee.
"What most this wondrous beast is like
Is mighty plain," quoth he,
'"Tis clear enough the Elephant
Is very like a tree!"

The *Fifth*, who chanced to touch the ear,
Said: "E'en the blindest man
Can tell what this resembles most;
Deny the fact who can,
This marvel of an Elephant
Is very like a fan!"

The *Sixth* no sooner had begun
About the beast to grope,
Then, seizing on the swinging tail
That fell within his scope,
"I see," quoth he, "the Elephant
Is very like a rope!"

And so these men of Hindostan
Disputed loud and long,
Each in his own opinion
Exceeding stiff and strong,
Though *each was partly* in the right,
And *all* were in the wrong!

Meeting Reports

SYDNEY SUPPORT GROUP

Toongabbie School
4th September 2010

Present: Kim K, Kim S, Jeanette & Henry B, Vera R, Jan McL, Frank M, Bernice & Bob R, Marion A, Ann & Lawrie P, Stewart & Gundel B, Ian L, Celia C, Emily S, Marj & Ken.

Apologies: Elizabeth & Lloyd (Lloyd is not well- get well soon, Lloyd!),
Jocelyn, Peter H, Keith & Hilary (Hilary is still not well enough to return following her spinal surgery, (we wish you a speedy recovery, Hilary).

Jeanette: Saw Dr Dexter recently regarding her MRI. The artery is still in the same place as before her stroke and he can see scarring further down. She said he had a lot more to say & is writing it up in a medical journal, so she hopes to bring a written copy next time as there was a lot she didn't grasp.

Marion: 2 years since MVD & all is well. Has occasional "funny" feelings, but dismisses them!

Stewart: He is about the same, on Amitriptyline. He copes.

Vera: Is doing well and has noticed improvement in her back pain by practising the 3 Acupressure points shown to us by Chinese doctor, Dr Sun at our August meeting. She does the below knee acu-point 2-3 times per day.
Kim K also mentioned she has had success with the first acupressure point on the hand with eliminating headaches, almost instantly!

Jan: It has been two & half years since her MVD & she is fine, no pain. She notices when she is tired she has pressure behind the eyes & some lip numbness.

Marj: They couldn't attend the last meeting as they were celebrating their eldest grandchild's engagement. Marj reports her pain is under control with meds. She has noticed she seems to have spikes in her pain levels with changes in air pressure & temperature.

Bernice: After 23 years of pain, Bernice had an MVD with Dr Dexter in Feb and happily reports she has been pain free ever since. She is not on any medication and feels like she is a new woman. She thanked the Support Group as it was only through our meetings & newsletters that she learnt about the MVD procedure. She is so grateful for the information & help she has received. She recently had to have a BCC removed from her cheek and is happy to report there were no problems with the procedure.
It's good to see you looking so well, Bernice.

Norma: Frank updated us on Norma, as she is busy at home with their great granddaughter. Norma had radio frequency some 30 years ago which has unfortunately left her with a numb face & damage to her eye. She is not on any meds, but has had a few bad 'ticks' lately.

Ann: she had an MVD which gave her 12 months pain free, then had radio frequency which put her jaw out and caused other problems. If she had her time over she would have had a second MVD, but the Dr at the time would not do a 2nd op. She doesn't have any pain is not on medication.

Celia: After many anxious moments, Celia had her MVD in June 2010. She has been pain free ever since, and is almost off all her meds. She is feeling a bit depressed lately & thinks it may be due to having back pain, and hopes her mood will lift when her back improves. She is very happy with Dr Dexter & looking forward to a pain free future.

Kim K: She is fine, pain is under control with 400mg SR Tegretol, provided she remembers to take them!

Kim S: Pain got totally out of control a few months ago & she ended up in hospital. She saw Dr Dexter again & opted for a second MVD, in June. So far, so good, she is coming off her meds & looking forward to continuing to be pain free. *We hope so too, Kim.*

Ian: Pain is still hanging around, and is on both sides! The left side is now worse than the right, but it is still relatively mild. The fear is always in the back of his mind that it will become more severe. (*We can all identify with that fear, Ian!).* Ian had his MVD 2 1/2 years ago & Dr Dexter could see no compression at all on the left side. He is not on any meds, but the worry of what might happen is the worst part. We all agreed it is very difficult to overcome that fear. He is not sure what his options are as Dr Dexter cannot see any compressions.

Emily S: We welcome new member Emily. Her pain started in Oct 2009, right side along the jaw line. A sharp, shooting pain and her dentist removed a wisdom tooth, but by April she was in extreme pain. Her GP referred her to Dr Vickers, who started her on Neurontin & Tegretol, but she had an allergic reaction, so went on to Lyrica. She was still in pain, so she saw Dr Dexter and had her MVD on 9th July. She happily reports that she has had no pain ever since & is feeling stronger every day. She is still tapering off her meds. She also said her Mum suffered with TN when she was 46 and had it for 15 years, this was back in the 70's and she had an injection (not sure what it was, alcohol, maybe?) and has been pain free for 19 years.

Kim K said her Mum, who is in her 80's and lives in Malaysia, is now getting TN pain! Kim sends her B12 (methylcobalamin) which has reduced her pain to a minimal level.
Kim K demonstrated the pressure points that Dr Sun showed us, for the benefit of those who weren't at the previous meeting.

We then welcomed Dr Joseph Ierano who gave us a brief run down on his work with TN patients. He trained in the USA in the Atlas Orthogonal Chiropractic field. Atlas Orthogonal is a chiropractic technique that specialises in the diagnosis & correction of improper neck function
He assesses patients' body balance & posture and requests a specific x-ray to give a clear picture. His manipulation techniques are very gentle & delicate.
He kindly checked the necks of several members, only to find various degrees of tension & knotted muscles! We thanked him for his time & informative talk.

The Fathers' Day raffle was won by Ian. Congratulations!

Frank reports that the Balance brought forward from July = $100.60
September meeting raffles raised $ 56.00
Less Hall Hire and Guest Speaker's gift $63.00
On hand = $93.60

Reminder: Dr Dexter will be speaking at our December Christmas combined meeting, here at Toongabbie. We also hope Canberra members will be able to join us for the December meeting.

Meeting closed at 4.00pm and we were spoilt with a beautifully decorated Pavlova as our 10th birthday cake! Thanks Kim K.

Next meeting 6th November 2010 - 1.30pm

Thank you, Marion for the meeting report.

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BRISBANE SUPPORT GROUP

Bridgeman Down

11th September, 2010

Present: Arthur C, Narelle C, Margaret O, Maree O, Neil F, Lorraine B, Jeff B, Helen W, Henry C, Eillen C, Margaret B, Colin B, Doreen T, Alzira D, John D, Tony M

Apologies: Leonie G, Margaret H, Noela W

We extended a very warm welcome to our new members with us and then shared our stories.

Narelle had her first bout 2 years ago, with recurrence 10 months ago. Both bouts followed periods of stress. Initially, diagnosis took some time, with doctors suggesting a pinched nerve that would go away. A CAT scan followed. Pain behind eye recently has been extreme, akin to a red hot poker and electric shock. An eye specialist has now diagnosed TN. Narelle is about to see a neurologist and currently takes 4 magnesium pills a day plus Remotive, a stress reliever.

Margaret O was diagnosed by a dentist on her first visit with symptoms 9 years ago. She also suffers rheumatoid arthritis and wondered if the TN was related to this. Pain was so bad that eating was affected, resulting in a 6kg weight loss. Following an MVD, she was pain free for 5 years, taking Lamictal as well. Pain returned 4 years ago, again affecting eating and teeth brushing. This has continued till 7 weeks ago, when it became excruciating. Tegretol caused constant vomiting, though the pain eased. She was hospitalised with a saline drip at this time. On visiting the neurosurgeon, he discovered an aneurysm post MRI and she is now considering radiofrequency.

Neil F has recently tried Himalayan crystal salt, which migraine sufferers use. He considers this to be of some benefit.

Lorraine is still on 200mg Lyrica. A dose beyond this causes a rash. She also takes 50 mg Endep at night and this assists sleep. She continues with the monthly methylcobalamin injection. Initially, this resulted in improvement, but pain has returned to tongue and jaw. She also takes magnesium, zinc and fish oil.

Helen had pain commence 2 years ago, and it took 5 months to be diagnosed. She commenced Tegretol and it took a month to become pain free. Pain returned and in March this year, was admitted to the Wesley as medication wasn't working. This visit resulted in a successful MVD by Dr Coyne, with subsequent lowering of Tegretol dose to current 100 mg with no pain.

Henry continues to be well. He was first diagnosed in 1997 and on Tegretol for 10 years, with pain all through that time, though the initial 200mg dose did work well for a short time. Since beginning neo B12 injections last year, fortnightly at first and then monthly, he is a new man and is now essentially pain free and off Tegretol.

Margaret B was first diagnosed in 1996. Dentists removed nerves from 3 teeth which did not help. X rays confirmed that teeth were not the problem. Tegretol CR did initially control her pain, but she ended up on many medications; at one stage, 22 tablets a day. Stress is a trigger. Margaret and two others in our group suffer also from tinnitus.
Margaret spoke of one TN shock so severe that a black burn mark appeared on the lip and remained for 3 days. Improvement came with commencement of neo B12 injections along with folic acid, Bio C, magnesium, German lecithin and flaxseed oil. She is now down to 400 mg Tegretol.

Doreen is on monthly neo B12 injections and going quite well since commencement. She also takes magnesium, folic acid and gingko. She is now down to 50mg Tegretol in morning and lunch, with only the occasional small stab.

Mary was on 3600mg Neurontin last year. She was advised that the maximum dose ought to be 1800mg. She had tried Tegretol, but she felt a "cotton wool" sensation in the head. Mary continues with B12 lozenges and since May has reduced to 300 mg Neurontin with 25 mg Endep at night and is going really well.

Alzira expressed her gratitude in discovering that she is not alone in her struggle. Her pain began last year in November. She was to see four dentists, with work being done which did nothing to reduce the pain. In one case, one molar was broken into several pieces. She also tried four different drugs including an antibiotic. When finally diagnosed and put on Tegretol, she found this to affect her memory as well as the sensation that it was eating the bones. She does find that very deliberate concentration upon an activity to be complete assists, as does prayer.

Tony continues frequent exercise, monthly methylcobalamin injections, magnesium, lysine, folic acid, executive stress tablets and flaxseed oil. A very positive approach incorporating humour and prayer helps get through rough patches. Improvement continues and though there have been some hits, return to work part time has occurred. He is off all medication.

Thanks to all for your stories. Our collective struggles show us that we need to do more in our Brisbane area to promote education in dentistry and medical circles so that a more rapid diagnosis can occur. We will discuss further an action plan at our next meeting.
Thanks to all who assisted with afternoon tea. Good wishes to all who can't be with us today. We hope you are well and that we can again share some time with you.

Gold coin collection: $ 27.00

Next meeting: November 13

Tony.

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SUNSHINE COAST SUPPORT GROUP

Kawana Library, Nanyina Street, Buddina.
18 September 2010

Jean opened the meeting: It's nice to see everybody. Thanks for taking the time to come, it is much appreciated. For those who couldn't make it we hope things improve, our thoughts and prayers are with you. Pearl came forward to take the meeting minutes. (Very much appreciated, thanks).

Apologies: Patricia O, David G, Max H, Teresa M.

Present: Jean W, Jean B, Glenda & Peter W, Jane K, Peter & Pearl R, Trixie B, John B.

Phone and email reports:

Patricia O: She has been to the dentist with a toothache, turns out it is TN. Patricia now has it on both sides. At the moment, she will see a Neurosurgeon at the Wesley in Brisbane. Hopes to get the MRI that she so badly wants. Patricia is hoping to see the gang next time.
*(Please remember - MRI is **not** a diagnostic tool for TN - Irene)*

David G: A few stabs a couple of weeks ago, nothing at the moment. He is so sorry that he can't attend.

Max H: Has some sort of wog that started last night. He has stopped all his medication (Tegretol). Only has to take one occasionally.

Teresa M: Sorry she can't attend. Teresa sounded as though she had the flu, but that wasn't the issue. Teresa had a family situation that she had to attend to. She hopes that someone will come forward and take the report.

General Business:

Jean needs someone to help. Whether it be advertising, picking up keys, organizing afternoon tea or taking reports. Jean works full time, 5 1/2 days a week, hence the reason that she is still in her uniform. Because she couldn't get all her quotes done, she has had to push some to next Monday. (Not good for business). Please don't say you can't help, walk a day in her shoes.

Advertisements have appeared on TV, radio & local newspaper. No one has seen them from the group. Good news though, Susan (from NZ) had & was ecstatic, there isn't a support group in Auckland. Jean and her husband met with her and spoke about her journey. It was good to see both husbands supporting each other. Susan took information back with her and she was advised to give Irene a call.

Group Reports:

Glenda W: Had a MVD in August with Dr. Sarah Olsen. The operation wasn't as successful as there was a vein that the Doctor couldn't reach. Glenda is now seeing Dr Leigh Atkinson. She is on a lot of medication still. Lamictal 25 mg 1X1, Gabapentin 100mg 3 time a day, Tegretol 1000g X800g. Glenda has found that taking this amount of medication, she is forgetful. (Maybe we all are). Peter has been there for support.

Jean B: Free of pain for about 6 weeks, really good. Jean had some sort of turn and was found unconscious. She had to have an injection at Nambour hospital, to bring her around. They kept her in intensive care for two days. Took more than two months to get over it. She had an infusion for the TN & the doctor said if her pain returned, she would have to have one again. Jean uses wheat grass cream, just rubs it on her face, it may help. Takes Gabapentin 300g-200g-300g. Had surgery MVD and 3 injections. She can't have any more as she has a pacemaker and takes Warfarin, because of this she has to have a blood test every week.

Jane K: Good to see you again. Jane has a two hour trip to get to the meetings. Support Groups give information, but also don't make you feel so alone. Her neuralgia is in V1 & V2. Occasionally takes Epilim goes up to 200mg . Her triggers are cold and wind. This year she has done really well. She has learnt to manage by being prepared for the triggers. At times she uses heat if needed and uses capsicum cream and pain patches.

Lloyd K: Originally got the pain 2 years ago when he went swimming. He went to see Dr Dexter and that was when he got marvellous relief (had MVD). Life is good for Lloyd and he is happy to help. He remarked that he is a little tender around his scar. Jean recommended a little pawpaw ointment may help soothe it. Very happy without the neuralgia pain. Any side effects would be better. When he was on medication, he wrote off his wife's car. (Not a good thing).

Peter R: A little more pain. He was on holidays and got fresh stabs, he upped the Tegretol to 400g (from 200g). If anything major happens he will go see Dr Dexter again.

Trixie B: Reminded everyone that Andrea is having her surgery in Sydney next week. She couldn't have the medications and is looking forward to a good result. Trixie has had no side effects since her MVD in February. She feels it has been 100% successful. Very glad to have gone to Dr Dexter. Trixie will organize the milk for afternoon tea and if she isn't here, Glenda will attend to it.

Jean W: She has gone back to see Dr Dexter, he doesn't think it is neuralgia. The MRI shows that the pain may be coming from her eye because of scar tissue behind her eye. So, she needs to go back to her Ophthalmologist. Jean had two detachments top and bottom, five years ago. At the moment she is on Gabapetin 300mg twice a day. Increasing this, by one every week until the pain is under control (not to exceed 2,400mg per day). She is hoping that she doesn't have to lose her eye. At this time she is waiting to get into the pain clinic at Selangor, can't get an appointment until December. (If she is cranky you know why).

Our next meeting will be our Christmas one. If everybody would bring a small plate of Christmas fare that would be lovely.

Next Meeting: November 20th at 1pm, Kawana Library.

Jean.

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Laughter is the best medicine…

1. HOW DO YOU DECIDE WHOM TO MARRY? (written by kids)

You got to find somebody who likes the same stuff. Like, if you like sports, she should like it that you like sports, and she should keep the chips and dip coming. - Alan, age 10

No person really decides before they grow up who they're going to marry. God decides it all way before and you get to find out later who you're stuck with. - Kristen, age 10

2. WHAT IS THE RIGHT AGE TO GET MARRIED?

Twenty-three is the best age because you know the person FOREVER by then. - Camille, age 10

3. HOW CAN A STRANGER TELL IF TWO PEOPLE ARE MARRIED?

You might have to guess, based on whether they seem to be yelling at the same kids. – Derrick, age 8

4. WHAT DO YOU THINK YOUR MOM AND DAD HAVE IN COMMON?

Both don't want any more kids. - Lori, age 8

5. WHAT DO MOST PEOPLE DO ON A DATE?

Dates are for having fun, and people should use them to get to know each other. Even boys have something to say if you listen long enough. - Lynnette, age 8 (*isn't she a treasure*)

On the first date, they just tell each other lies and that usually gets them interested enough to go for a second date. - Martin, age 10

6. IS IT BETTER TO BE SINGLE OR MARRIED?

It's better for girls to be single but not for boys. Boys need someone to clean up after them.

- Anita, age 9 (bless you child)

7. HOW WOULD THE WORLD BE DIFFERENT IF PEOPLE DIDN'T GET MARRIED?

There sure would be a lot of kids to explain, wouldn't there? - Kelvin, age 8

8. HOW WOULD YOU MAKE A MARRIAGE WORK?

Tell your wife that she looks pretty, even if she looks like a dump truck. - Ricky, age 10

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2010 Meeting Dates

State	GROUP	Date & Time	Venue	Group Leader/s
ACT	**Canberra**	**25 September** **10.30am-12.30pm**	**Barbara Byrne Room** Labour Club, Belconnen	Jan Goleby ☏ 02 6254 6640
NSW	**Sydney**	**6 November** **1:30 – 4:00 pm**	**Toongabbie Public School** Cnr Fitzwilliam & Binalong Roads	Kim Koh ☏ 02 97431279
	Sydney CBD	**4 December** **10am –12:30pm**	**Toongabbie Public School** (Combined meeting)	Irene Wood ☏ 0413 363 143
QLD	**Brisbane**	**13 November** **1.30-4.00pm**	**30 Ridley Road** **Bridgeman Down**	Leonie Gall ☏ 0407 55 44 07 Tony MacPherson ☏ 07 3822 2286
	Sunshine Coast	**20 November** **1:00 pm**	**Kawana Library,** Nanyima Street, Buddina	Jean Williams ☏ 07 54911978
	Townsville	**20 November** **1.00 – 4:00pm**	**Carville Senior's Villa** 35 – 37 Diprose St Pimlico	Sera Ansell ☏ 07 47516415
S.A	**Adelaide**	**28 November** **2pm – 4:00pm**	**Burnside Town Hall** **Civic Centre** Cnr Portrush/Greenhill Rd	Graham/ Liz Boyer ☏ 08 8392 2781
TAS	**Hobart**	**20 November** **2:00 – 4:00 pm**	**Glenorchy Library** Enter via **Barry and Cadell Sts**	Helen Tyzack ☏ 03 6245 0429 Ros Wilkinson ☏ 03 6234 7989
VIC	**Melbourne**	**2nd October** **1.30 – 4:00pm**	**"Ringwood Room"** **Ringwood Library,** **RINGWOOD**	Evelyn Diradji ☏ 03 9802 6034

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