

February Newsletter



Eight Questions to Ask Your Doctor Before an Invasive Medical Procedure

By Melissa Wardlaw | An excerpt from nationalpainreport.com
A recommended read by Pain Specialists Australia.

1) How many times have you performed this procedure and when was the last time?

Make sure the procedure is something the doctor is experienced at doing and does on a regular basis. If he can't answer when the last time he performed the procedure was, this probably means it's not too common for him and you might consider going to a different doctor.

2) Can you please walk me through what will happen before, during and after the procedure?

The doctor should be able to tell you in detail what the process entails from beginning to end – with confidence.

3) Have you ever had any complications?

Most doctors will have had at least a few complications in their years of practicing medicine – the key is, what happened during these complications. For example – Were they major or minor? How did he react during the complication(s) and what did he do to counteract the complication(s)?

4) What are my chances for success?

The doctor should be able to give you some sort of guide or statistics for what to expect as far as what the procedure will do for you and your condition.

5) What are the percentages of success you've had in other patients – referrals?

6) Have you ever been sued for malpractice? Trying to determine if the doctor has any malpractice suits related to the specific procedure(s) you are considering and if so, what were the issues surrounding it.

7) Can you please elaborate on (X, Y, Z) internet review?

8) Are there any alternatives for me besides this procedure?

Before going through any invasive procedure, it is imperative that you are 100% sure the benefits or potential rewards outweigh the risks or potential side effects.

tnaaustralia.org.au

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, leading to better pain management.

Our Vision:

An improved Quality of Life.

A comparison of microvascular decompression (MVD) surgery versus stereotactic radiosurgery (SRS) for trigeminal neuralgia

Benjamin Jonker | Neurosurgeon

Patients with trigeminal neuralgia will sometimes receive different advice depending on which doctor they see for their problem. It is always helpful for people to have an understanding of the pros and cons of different approaches.

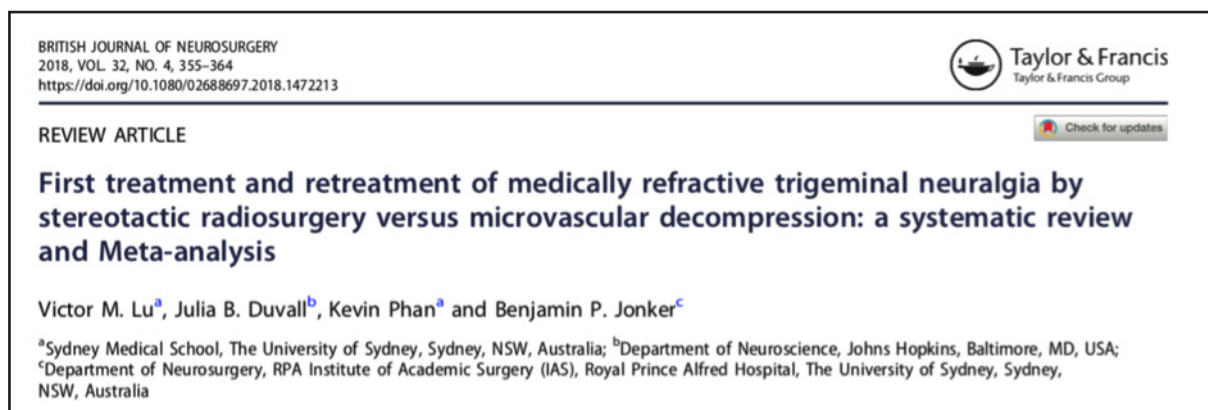
The procedures in brief

Microvascular decompression (MVD) is our gold standard surgical procedure for trigeminal neuralgia involving an operation under a general anaesthetic through a cut behind the ear. It is highly successful, but obviously requires some time to recover from and there are a few serious but thankfully rare risks.

Another approach to trigeminal neuralgia, which has been particularly popular in the United States and Europe and to a lesser extent in Australia is stereotactic radiosurgery (also known as Gamma Knife if that particular brand of machine is used). This is a non-invasive procedure where multiple pinpoint beams of radiation are focussed onto the trigeminal nerve with the aim of stopping the excitability of the nerve that causes trigeminal neuralgia. It requires no anaesthetic or recovery time and doesn't even require people to come off blood thinning medications.

How do we work out how to proceed?

One of the methods used in medical research when there are a large number of studies with information available is to do what is called a "systematic review and meta-analysis". This entails finding all the relevant published papers that exist on the topic, and where possible numerically combining all the data using statistical methods to try and get the most comprehensive information on the topic.



Our systematic review of MVD versus SRS

In 2018 I published a systematic review and meta-analysis with my co-authors in British Journal of Neurosurgery. We sought to find all the relevant data that would allow us to compare surgical microvascular decompression (MVD) with radiosurgery (SRS). We found 532 papers in the medical literature, and after removing duplicate publications and seeing whether the papers addressed our topic we were left with 39 studies. These included 1353 patients of which about half received MVD and the other half received SRS.

Whereas MVD had 91% of patients pain free after the procedure, the number was less for SRS with 66%. In other words MVD made 9/10 patients pain free, but SRS made 2/3 patients pain free.

Some patients will experience a recurrence over time but we also found that a number of years after treatment the proportion of pain free patients remained significantly higher with MVD compared to SRS.

Complications were more common in the MVD group than after SRS with CSF leak (brain fluid leak), loss of hearing on the side of surgery and wound infections being the most common.

We did, however find that SRS showed a greater association with facial numbness or abnormal sensation than did MVD. This was not unexpected, since the purpose of the radiation is to dampen down the firing of the trigeminal nerve.

What does this mean for me?

The take home message is that MVD remains the most effective procedure for trigeminal neuralgia, and for this reason it is the treatment of choice in most patients who need a procedure for their TN, if they are otherwise healthy (or have manageable medical problems).

SRS (radiosurgery) is less effective, but the majority still obtain pain relief and it has a very low complication rate (aside from facial sensory changes). For this reason, patients with significant medical problems, or who can't afford to be taking a number of weeks off to recover from their procedure may benefit from undergoing SRS.

I hope this has contained some helpful information. Please remember that this information is general and for an individual patient it is always advisable to discuss treatment options with an experienced practitioner!

Ben Jonker



Dr Jonker is an Australian neurosurgeon with special expertise in Stereotactic and Functional Neurosurgery. He completed his neurosurgical training in some of the best hospitals in Australia, and subsequently was selected for subspecialty training in Stereotactic and Functional Neurosurgery in Calgary, Canada and UCLA Los Angeles.

Dr Jonker has a particular interest in conditions treated with stereotactic and functional neurosurgery – and treats these with both open or minimally invasive neurosurgery, stereotactic radiosurgery, and MRI-guided focussed ultrasound.

Dr Jonker operates at Royal Prince Alfred Hospital, Chris O'Brien Lifehouse at RPA and St Vincent's Hospitals in central Sydney. He consults in Sydney and Orange.

Time to Take Back Your Life!

Let 2019 be the year that you set goals and tick them ALLLL off!

The Five Golden Rules

1. Set goals that motivate you.
2. Set SMART goals.
3. Set goals in writing
4. Make an action plan.
5. Stick with it!

Tip:

To make sure that your goal is motivating, write down why it's valuable and important to you. Ask yourself, "If I were to share my goal with others, what would I tell them to convince them it was a worthwhile goal?" You can use this motivating value statement to help you if you start to doubt yourself or lose confidence in your ability to actually make the goal happen.

SMART Goals are:

Specific. Your goal must be clear and well defined.

Measurable. Include precise amounts, dates, etc so you can measure your degree of success.

Attainable. Make sure that it's actually possible to achieve the goals you set.

Relevant. Goals should be relevant to the direction you want your life and career to take.

Time Bound. Your goals must have a deadline so that you know when you can celebrate success.

Write it Down!

The physical act of writing down a goal makes it real and tangible. You have no excuse for forgetting about it. As you write, use the word "will" instead of "would like to" or "might."

Post your goals in visible places to remind yourself every day of what it is you intend to do. Put them on your walls, desk, computer monitor, bathroom mirror or refrigerator as a constant reminder.

Action Plan

This step is often missed in the process of goal setting. You get so focused on the outcome that you forget to plan all of the steps that are needed along the way. By writing out the individual steps, and then crossing each one off as you complete it, you'll realize that you are making progress towards your ultimate goal. This is especially important if your goal is big and demanding, or long-term.

Don't Give Up!

Remember, goal setting is an ongoing activity, not just a means to an end. Build in reminders to keep yourself on track, and make regular time-slots available to review your goals. Your end destination may remain quite similar over the long term, but the action plan you set for yourself along the way can change significantly. Make sure the relevance, value, and necessity remain high.

Excerpts taken from mindtools.com

Check out the fitness goals being ticked off so far this year by Lauren in the Melbourne TN group! Her motto is 'STRONG 2019'. Well done on your personal goal setting, Lauren!



My TN Journey

Barbara | Melbourne | January 2019

I wish to share my story of Trigeminal Neuralgia in the hope that maybe one of my treatments will assist you in finding a cure.

In August 2003, at the age of 74, I was diagnosed with Trigeminal Neuralgia. Initially, for the first month, I was prescribed TEGRETOL. However, the TEGRETOL induced Hepatitis and I ceased use. The TEGRETOL was replaced with a combination of LYRICA and NEURONTIN. In the early period of TN diagnosis, I was receiving an acupuncture treatment, which I felt gave me short term relief. At this time, the TN spasms were sporadic. After approximately 2 years of acupuncture it became evident that it wasn't controlling the pain. Over the next nine years the TN pain became more intense and therefore my medication was gradually increased.

By May 2012 the LYRICA and NEURONTIN wasn't sufficiently relieving the TN pain and Surgeon# 1 performed "a right trigeminal nerve microvascular decompression procedure". After this I was pain free and managed to wean LYRICA from 450mg per day to 25 mg per day. And ultimately, ceased medication completely. However, unfortunately, I didn't stay pain free for long and from November 2012 I was back on the LYRICA and NEURONTIN.

Over the next 4 years the TN pain became completely debilitating. My Neurologist was most concerned for my condition and regularly expressed sincere sympathy to my plight. I was one of his more 'difficult' patients to cure. I was on the highest possible dosage of LYRICA, boosted with NEURONTIN, and they weren't relieving the pain. In 2005 I'd had an operation for clipping of an aneurysm following a subarachnoid haemorrhage and my Neurologist was loathed to recommend further surgery. At times, when the pain was unrelenting, I was prescribed ENDONE and, on several occasions, I was admitted to hospital primarily to assist with pain management and rehydration. There wasn't any quality of life. I needed to seek a another opinion.

In April 2016, from Surgeon# 2, I had "a right sided glycerol injection to Meckel's cave". Unfortunately, it didn't ease the pain for long. So, in August 2016, I had "an injection to my right infraorbital nerve using a combination of local aesthetic and steroids", from Surgeon# 2. The pain was minimised for a few months. However, in hindsight, I think that when the anesthetic from the procedure wore off the pain returned.

Then in early March 2017, Surgeon# 2, performed a "right infraorbital and supraorbital nerve blocks". This last procedure didn't ease the spasms, if anything they were coming more frequently, to areas I'd not experience pain before and, as-well-as the 'shocks', I started to experience a hot/burning sensation. During all these procedures I was still taking the LYRICA and NEURONTIN.

Earlier I mentioned there wasn't any quality of life. The TN was dictating how I lived. With the high doses of medication I slept a lot. I was too scared to scratch my face, eat, drink, talk, brush my teeth and comb my hair; because I was in fear of experiencing an excruciating spasm, which were occurring numerous times during the day and night. Due to the increased frequency of the spasms, I found it difficult to arrange social engagements with friends as more often than not arrangements would be cancelled. I was beside myself.

A few weeks after my last procedure I heard about another treatment and in late March 2017, Surgeon# 3 performed a "right V2/V3 radiofrequency rhizotomy". It seemed to hold the TN for a while. If my memory serves me correctly, I began weaning off the LYRICA and NEURONTIN. However, I was still experiencing slight 'twinges'.

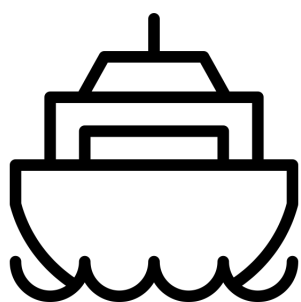
In July 2017, Surgeon# 3, performed a "redo right radiofrequency Rhizotomy". Once again, he prepared me to the fact that with this procedure I may lose sensitivity in some areas of my face. At the time, I felt the TN pain levels far outweighed any nerve loss.

It's now 18 months since my last TN treatment and **I'm thrilled to report I'm pain free.**

A month ago, LYRICA prescription was reduced to 75 mg per day and am functioning to the best of my ability. After the operation I did experience some nerve loss. However, considering the pain I'd had, the inconvenience has been minor.

Surgeon# 3 isn't sure how long I will remain pain free, however, I have been advised the procedure can be repeated. It's been a 14-year journey, at times extremely debilitating and it hasn't been easy sourcing the various surgical treatments. I hope that my story will encourage you to keep searching and maybe introduce you to treatment you didn't know about. My best wishes, stay strong and here's to a pain-free life.

TN Buddies



Brisbane Support Group
December 8, 2018 | 30 Ridley Rd, Bridgeman Down

Attendance: Anita M, Margaret M, Mary M, Christine M, Ken B, Margaret and Colin B, Sue L, Marie and John K, Tony M

Apologies: Maria K, Dorothy W, Steve O

Coin donation \$45.00

Our meeting began with Dorothy's story. She can't be with us today, but wanted us to know how well her recent gamma knife procedure went. She experienced excellent service and support before, during and after the procedure. Steve O is now based in Victoria and has been able to return to work following his successful MVD. He has experienced no pain since the operation. Both send warm wishes.

We then shared our stories.

Sue had an MVD four years ago, but pain has returned. She has had a bad reaction to tegretol and is now on gabapentin. She has noticed that the pain appears different to earlier bouts. She is planning to have a neurosurgery consultation later this month.

Marie is not travelling well since stopping tegretol and switching to trileptal. The pain did stop, but she experienced side effects at the higher trileptal dose.

Ken has been able to keep attacks at bay on 600mg Neurontin bd and 400mg tegretol bd. He occasionally gets some minor pain at night but this is tolerable.

Mary is going really well with no pain. She had a gamma knife procedure last October and has reduced medication to 150 mg trileptal bd.

Margaret M is experiencing some pain with eating, drinking and being in the wind. She is having another MRI next February. She currently takes 300mg lyrica bd and 10mg endep. Despite pain, she still likes to have a go at playing tennis. Well done Margaret!!

Christine continues to be absolutely pain free following her MVD in Sydney. She said that even with TN, she continued playing golf and found she had no problems with the wind.

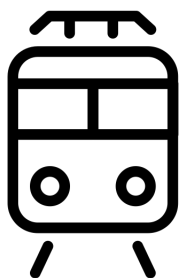
Margaret B has had a tough year and is glad to be able to be back with us. TN returned in February and also noticed pain in both arms and was diagnosed with polymyalgia rheumatica, resulting in prednisone medication. She has also been diagnosed with occipital neuralgia as well as TN. This is Margaret's 20th anniversary with TN. (If only we'd known in advance, Margaret, we could have baked you a cake!!)

Anita has had MS for twenty years and TN would come and go with breeze, heat, brushing teeth etc. She has noticed that stress is also a trigger, and many in our group have reported this link as well. She is currently on tegretol but has not reacted well to it. She finds balance affected. She is on a T cell trial.

Tony is still TN pain free without a major hit since MVD in August 2016! Some minor rumblings occur from time to time with temple pain on both sides, but nothing like the horrors of pain pre MVD.

Thanks to all who supplied goodies for our Christmas party today. We wish all members around the nation wellness for the year ahead.

Next Meeting: Saturday February 9 and then every second Saturday of every second month throughout the year: ie April 13, June 8, August 10, October 12, December 14.



Melbourne Support Group December 8, 2018 | Maroondah Federation Estate

Attendance: Joy & Alan C, Sabina G and Matt P, D'arne Reid, Elaine A, Jean I, Jenny & Chris H, Julie Z, Barbara E, Lauren G, Kathy & Norm C, Joan & Neil T, Beryl & Rob O, Will & Joan R, John S, Murray & Helen C, Stephen W, Robert & Nita M, Alister S, Catherine T.

Apologies: Emelye L, Leanne P.

New Member Stories:

Alister works with horses and was accidentally struck in the face by a horse, causing an orbital fracture and nerve damage. He has had 14 months of pain and double vision and is looking for a specialist who can understand and help. The group recommended a Melbourne-based pain specialist.

D'arne was recommended to attend the support group by her neurosurgeon for extra coping support. She had an MVD, which offered complete pain relief for three months before the pain - very sadly - returned. She has tried two glycerol injections, but nothing is completely taking the pain away. Her pain is atypical TN. The next plan is to try radiofrequency. Unfortunately D'arne had to leave the group early as she found the room too echoey/noisy.

Support Groups



Sydney

Shane Thein – tel: 0407 106 470



Melbourne

Emelye Lovell – tel: 0400 004 110



Adelaide

Graham Boyer – tel: 08 8392 2781



Brisbane

Tony MacPherson – tel: 07 3822 2286



Gold Coast

Peter Gough – tel: 0414 233 044

Brian Feeney – tel: 0401 312 775



Sunshine Coast

Nora English – tel: 0418 495 776



Mackay

Vicki Brown – tel: 07 4956 3468

Mackay Support Group

Harrup Park Country Club,
Juliet Street, Mackay from 1:30pm
March 3rd
June 2nd
September 1st
December 1st

Sunshine Coast Support Group

Kawana Library, Nanyima Street,
Buddina, QLD from 1:00pm
For next meeting details:
Nora English – tel: 0418 495 776

Melbourne Support Group

Room 4, Maroondah Federation Estate
32 Greenwood Avenue, Ringwood, VIC
1:30pm to 4:00pm
Saturday February 9
Saturday April 13
Saturday June 8
Saturday August 10
Saturday October 12
Saturday December 14

Brisbane Support Group

30 Ridley Road, Bridgeman Downs, QLD
1:30pm to 4:00pm
February 9th
April 13th
June 8th
August 10th
October 12th
December 14th

Sydney Support Group

St. James Parish Hall, Level One,
169 Phillip St, Sydney, NSW 10:00am
6th April
1st June
3rd Aug
12th Oct
7th Dec

Gold Coast Support Group

Elanora Library
The Pines Shopping Centre
2nd February
23rd March
25th May

Adelaide Support Group

Burnside Town Hall Civic Centre
Corner of Greenhill Road and Portrush Rd,
Burnside, SA 2:00 pm to 4:00 pm
31st March

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