



Choosing a Surgical Procedure

Deciding what is the best treatment for your TN is sometimes a very difficult decision. The following ideas are taken from the TNA and outline some factors you need to consider.

Make sure of your diagnosis.

- Talk with your physician about classic trigeminal neuralgia versus neuropathic facial pain, or deafferentation pain. Many of the treatments for classic trigeminal neuralgia are not effective for other types of facial pain and could even make the pain worse.

Educate yourself

- Talk to others with similar symptoms.
- Search reliable web sites for additional information. A very good site is the University of Manitoba's site. Get the link from www.catna.ca
- Read the "Striking Back" book
- Read all available medical literature

Recuperation

- Consider how much time you can afford to spend recovering from surgery? Recuperation is faster for some procedures than for others.

Willingness to have a major operation

- General health and ability to tolerate surgical stress
- A MVD is major surgery and requires opening the skull to get to the trigeminal nerve as it exits the brainstem. On the other hand, an MVD actually protects the nerve by removing blood vessels that are compressing it.
- Other procedures are deliberately destructive: balloon compression, glycerol injection, radiofrequency lesioning, and radiosurgery (Gamma knife). All of these

cause some damage to the nerve in order to disrupt pain signals.

Branch of the nerve affected

- If the pain is in the first division there is a slight risk that the destructive procedures will leave the cornea of your eye with no sensation. The MVD has the highest rate in terms of preserving sensation in the cornea. For destructive procedures, some physicians recommend the balloon compression.

Facial numbness?

- The destructive procedures can cause numbness. Most people can tolerate it and it's far preferable to the pain of TN. However, some patients have found it extremely difficult.

Toleration of recurrence

- TN is more likely to recur with some procedures than others.
- The MVD, which is slightly riskier because it's major surgery, has the lowest rate of recurrence.

Accepting the Risks

- Can you accept the particular risks of the procedure you're considering? Do you know what the risks are? People are very different in the way they deal with risks; therefore, this needs to be a personal decision, not a medical one.

Willingness to travel

- If necessary, are you willing to travel to undergo a certain procedure or to see a particular physician?
- Some of the procedures are only offered in certain areas of the country.
- The more experienced physicians may not be in your area.
- Many physicians only offer one or two procedures.

- If the pain returns, do you have a local physician willing to manage the TN?

The decision

- Ask all of these questions, get complete answers, talk to people who have had the procedures, and get all the other information you can. With your physician, you can make a good decision about which procedure will be best for you.

Ask the Pharmacy

Derek, a Pharmacy Technician will get answers to all your pharmaceutical questions, just forward them to Jan at CaTNA. The addresses are on the last page of this newsletter.

Q: We've heard of patches for all kinds of drugs, are there skin patches available for drugs like Tegretol and would they be as effective as oral administration?

A: There are no patches for these drugs. However, a compounding pharmacy can prepare special creams. In Canada, the compounding pharmacies do not see a lot of this type of thing. They can make just about anything if the Doctor prescribes exactly how he wants it manufactured. The problem is not a lot of physicians are familiar with how to dose this way for drugs like Tegretol. So in short, yes it can be done, but you need a knowledgeable physician and pharmacy.

Q: I have recently started on Gabapentin (Neurontin). My doctor is increasing the dose slowly but I still have pain. How long does it usually take before a person knows if the Gabapentin will be effective?

A: Gabapentin is started on a titration dose depending on what the physician sees as the final maintenance dose. Doses of up to 2400 mg in 3 divided doses are usually well tolerated. Dosing of 1800 mg daily in 3 doses is often the usual range. The dose is often titrated up over 3 days depending on how well it is tolerated, though this will be slower in some patients. This drug has very high incidence for side effects of drowsiness and dizziness, so physicians often go slowly. If you have experienced some relief this is a good sign that the

medication would be effective. You should definitely talk to your doctor if you are not experiencing significant pain reduction. I do not know what your current dosing is, so it is difficult to judge for sure if you should increase the dose. After dose changes you should feel improvement in a couple of weeks for sure. You should probably not exceed 600 to 800 mg three times daily. If you are still having problems, there are other medications to try.

Q: Is there anything I can do to decrease the drowsiness I feel taking Tegretol? (you could pick any of the drugs)

A: One of the problems with Tegretol and some other drugs used for TN like Lyrica and Gabapentin is the common side effect of dizziness and drowsiness. Many patients find that these side effects decrease over time. Trying to find the lowest possible dose that controls symptoms is important with Tegretol to help minimize side effects. Taking medication at bedtime is useful if dosing regime permits. It is quite uncommon that patients would have to discontinue taking Tegretol due to drowsiness. Elderly patients and patients who were not started on a gradual dosing schedule would more likely suffer side effects. IN other words, start slowly, find minimum effect dose and stick with it.

Support Group News

Calgary

This group will meet the third Tuesday of each month at 1 pm at Confederation Park Senior Citizens Centre, 1112 - 13 St. N.W. Room #4. Contact Bev for more information.

Note: there will be no meeting in June or July. The next meeting will be in August.

Regina

Meetings are held monthly at the Wascana Rehabilitation Center, 2180 - 28th Avenue, 2nd Floor, Rooms 1,2 & 3. Contact Faye for specific details.

Note: Regina meetings are suspended for the summer. The next meeting will be in September.

Niagara Region

Please contact Brenda for details on the location and date of the next meeting.

Toronto

The Toronto group meets at the Thornhill Community Centre, 7755 Bayview Ave. on the last Sunday of the month. 9:30 a.m.

June 27/10 July 25/10 August 29/10

Letters

Re: Radiofrequency Rhizotomy

Has anyone had this surgery? I am scheduled to have this done on June 18th at Sunnybrook and would appreciate any feedback about this.

I am 55 years old and after 2 1/2 years of pain I finally got some answers as to what I actually have and am having this surgery. The pain was getting so bad, that there were times that when a shock hit would hit and my whole right cheek would visibly twitch. If I was outside and there was a small breeze I would be paralyzed. Lyrica and Tegretol did not help. Not being able to eat was the tough part and I lost 30lbs.

I finally quit my job as I was missing so much work, and when I could function, I was in so much pain I found it hard to concentrate. I am on now Gabapentin 300mg, 3 pills in the morning, 2 in the afternoon and 2 at night. I have been on this for almost 2 months and have only had a few very small shocks...just enough to remind me that it is still lurking there. Thank you.

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Vitamin B for Nerve Health

When you lack B vitamins, you may suffer pain in your hands or feet, signs of what's called peripheral neuropathy. The good news: B supplements can help your nerves calm down and stop screaming with pain.

Because nerves send impulses throughout the body, this condition can leave you with a host of discomforts: pain in your face, hands and feet; digestive troubles; and incontinence. But taking extra nutrients may help soothe your nerves and relieve pain by repairing and rebuilding the protective structures that usually protect your nerves.

B-Relief

Nerve damage can be caused by vitamin B deficiencies. All the members of the B vitamin family play crucial roles in promoting and insuring nerve health:

Thiamine (B-1) and biotin (B-7) promote healthy nerves. Riboflavin (B-2) aids in nerve insulation. Niacin (B-3) assists nervous system function, while pyridoxine (B-6) helps the body use and absorb niacin and B-12.

A lack of B-6 may cause carpal tunnel syndrome, painful neuropathy in your hands that may make it impossible to type or grip heavy objects. Also important is cyanocobalamin (B-12), which helps nerves function and avoid damage. Both B-12 and folic acid (B-9) deficiency can give you neuropathic leg and foot pain.

Nerve Health

Several studies in Japan, Germany and France have concluded that B vitamins enhance nerve health and help damaged nerves repair themselves. People with neuropathy who were given high doses of biotin noted marked pain relief within a couple of months.