



# Canada TN Association Newsletter

February 2010

## Greetings all

*In this edition, questions and answers about the MVD*

*I hope this newsletter finds everyone pain free and well recovered from the holidays. I'm getting settled here in British Columbia and thinking about seeing if there are folks in this area of South Surrey/White Rock with TN. Maybe we could start another group out here. If you would like to start a group in your area, please let me know and I'll try and help you get started. A group doesn't have to be a major undertaking – it can be just a few friends getting together to offer each other moral support. Think about it.*

*I am also looking for ideas for this newsletter. What would you like to see it contain? I would love to hear from you. Jan*

## Microvascular Decompression

### Introduction

Trigeminal neuralgia (TN) has been described in various medical journals for many years. In 1934, a Dr. Dandy developed a theory of vascular compression as a cause of TN. This was treated by severing the nerve completely. It wasn't until 1968 that Dr. Peter Jannetta decided to try a non-destructive approach and used a protective pad to hold the blood vessel away from the nerve. Today, the Microvascular Decompression procedure is the best option for most people looking for a permanent "cure" of TN.

### How is it done?

Patients are put to sleep using general anesthesia and are positioned on their back with their head turned or on their side with the symptomatic side facing up. An incision is made two finger breadths behind the ear about the length of the ear. A portion of the skull the size of a quarter is removed exposing the area where the trigeminal nerve is located. Using a microscope and micro-instruments, the trigeminal nerve is exposed. The offending loop of blood vessel is then identified and a sponge like material (Teflon) is placed

between the nerve and the offending blood vessel to prevent the vessel from returning to its original position.

### Recovery

After the decompression is complete, the wound is closed. The skull is reconstructed and the overlying tissues are closed in multiple layers. The patient is allowed to wake up and is taken to an ICU or other close observation unit for about 24 hours. Most people are kept in hospital for a further 1 – 2 days. Over a period of weeks the patient can return to normal activities. If the patient was on drugs for TN, these can be slowly withdrawn so that by the end of two weeks the patient is "drug free".

### Complications

Serious complications from an MVD include Death (0.1%), Stroke (1%), Hearing loss (3%), and facial weakness (.5%). Other complications include leakage of spinal fluid and wound infection (1%). These complication rates are generic from the literature and different neurological centers can have very different rates depending on the experience of the neurosurgeon and his/her team.

## Q & A

*The following questions were posed by Bonnie considering an MVD in Winnipeg and the answers were given by people who had an MVD done by Dr. Kaufmann.*

### 1) Were there any complications from the surgery?

- B - NO, but with MVD #2 I did have a small CSF leak but it was caught and corrected on the second day post op.
- C – No none
- L - No complications except nausea from the anesthetic - a normal thing for me.
- J – Nothing major

### 2) On a scale of 1-10, how painful was it immediately following surgery and how long did it last?

- B - The only pain that I felt was the granddaddy of all headaches, but ibuprofen took care of that. It lasted two days.
- C – Woke in recovery no pain, so zero on a scale of 1 – 10
- L - I had no pain immediately following the surgery. I was only sore from the surgery & incision.
- J – Some pain (big headache) for the first 12 hours – but drugs took care of that. No TN pain at all

### 3) Were there any problems or complications flying?

- B - NO and NONE. Air travel was a breeze.
- C – I expected pain with pressure changes, but there was none
- L - I drove to Winnipeg (from Calgary) with my husband.
- J – No trouble at all

### 4) Does the cold weather or weather changes still bother you?

Everyone said no

### 5) Do I need to have a wheelchair at the airport, or is walking no problem?

- B - I was able to walk, and I also have MS.

C – Felt a little weak but walking was no problem

L - Walking was no problem for me.

J – No trouble walking

### 6) How long was the recovery period?

- B - I felt great when the headaches left.
- C – It was about 6 weeks before I forgot I'd ever had TN
- L - I recovered very quickly, however because of the anesthetic I became very constipated & had abdominal pain for a couple of days.
- J – After about 2 weeks I felt great

### 7) How long until I am med. free?

- B - I was on carbamazepine and I reduced one (1) 200 mg tablet every fifth day, until there were no more.
- C – I tapered off over about 3 weeks
- L - Immediately after the surgery my medication was cut in half at the hospital. Then I weaned myself off all medications over a 2 week period.
- J – two weeks

### 8) Who took out the stitches?

- B - They dissolved, but a couple that still were visible on my skin, my wife removed. She is not a trained nurse.
- C – Stitches dissolved except for one metal staple that the GP pulled out
- L – A doctor in Calgary removed my staples
- J – Staples removed in Winnipeg and then the sutures dissolved on their own

### 9) How often did you have to follow-up with your Neurologist?

- B - I didn't follow up with anyone other than Dr. Kaufmann's nurse.
- C – They called me for regular reports
- L - Dr. Kaufman's nurse called me approximately 2 weeks after the surgery to see how I was & then went to see my GP.

**10) How long before I can sleep on that side again?**

- B - For me it was within a week.
- C – I slept on that side right away
- L - It took a few weeks before the incision was completely healed but once it was I was able to sleep on that side.

**11) How long until 100% pain free?**

- B - For me it was instantly, I woke up TN pain-free.
- C – Pain free right away but for about a week had an uncomfortable pressure feeling in my head.
- L - I was pain free immediately after the surgery & have not had any TN pain since. I did have some occasional aching on my right side, for a few months, but Tylenol took care of it.
- J – No major TN pain since the surgery but for several months had small tingling and "phantom" pains – nothing to require medication.

From Jo:

I had a couple of additional questions about MVD too....

- Q - How long is the typical stay in hospital after the surgery?
- A - The normal stay in a hospital after an MVD seems to be 1 - 2 days if all goes well - but ask the doctor about that because he'll have your medical records in front of him and can answer the question specifically for you.
- Q - Do they shave any hair off your head behind your ear?
- A - The amount of hair removed is very small - it is along the hairline behind your ear - probably about 1/2" wide about the length of your finger.
- Q - Is your whole head covered in bandages, or just the area that was operated on?
- A - Dr. Kaufmann and Dr. Kiss (Calgary) do not use any bandages. Most likely no one will even notice the incision if you

don't point it out because it is behind the ear. However, I've heard there is a neurosurgeon in Vancouver who applies a large bandage for 10 days.

**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. The next meetings are  
Feb 16 – 1 pm  
March 16 – 1 pm  
Contact Bev for more information.

**Niagara Region**

The next meeting will be Feb 21 at 1 pm – please contact Brenda for details on the location.

**Regina**

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

Next meeting:  
Feb 6, 2010 - 10 am

Speaker: **Dr. Buwembo, Neurosurgeon**  
Wascana Rehab Center – 1<sup>st</sup> Floor  
Auditorium

March 13 – Dentist to be determined later.

**Saskatoon**

No information available on future meetings. Please contact Dee for dates and times.

**Peterborough**

Marilyn is unable to continue to organize the meetings so if anyone is willing to come forward and take her place, please contact me (Jan).

## Toronto

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

Feb 28/10    March 28/10    April 25/10

May 30/10    June 27/10    July 25/10

August 29/10

The Toronto chapter would like to thank Dr. Kaufmann for attending our October dinner. It was a very informative meeting for all. I hope you all enjoyed dinner. I hope you all enjoyed meeting other TN people and those who support us. If nothing else it's a time to realize that you are not alone there are many of us with TN.

## A letter to a support group leader

Hello Brenda,

My name is Kevin and I am the youngest of the James Davidson family. I am sorry to say that my father James passed away Feb 22/09 in St Catharines with his family at his side. He was having trouble eating for the past 8 months or so. He went for numerous tests with no results for the abdominal pain he was having. Finally the pain was so bad we had to rush him to the hospital and found that he had 3 blocked arteries that were starving his colon and bowels.

His main concern going in to the emergency was that he had his pills for the T.N that he's been coping with for so many years. After his 3<sup>rd</sup> emergency operation on his bowel my mother & I went to see him learning they had taken him off the morphine he's been getting since first rushed in. The pain he was in even though he could not speak or open his eyes was so bad that it drove me nuts watching him.

I asked him if it was his face that was hurting so much and he nodded his head yes. They could not give him his meds for the T.N because he had to take them orally

& there was no way that could be done; I pleaded with the nurse to put him back on the morphine but she said it was out of her hands until the Dr. gives the ok to do so.

My Dad went through that pain all night and I could see that his face was twitching in pain every few seconds from the T.N.

His liver started to shut down & that's when the Dr asked if we wanted to pull the plug because he was not going to survive either way. I truly believe that the TN pain was so intense that he chose to throw in the towel instead of going through more of that pain. God rest his soul and I am happy that the pain is now over, I miss him so much and things have been so hard since with mom in bad health & no one there for her anymore. Your meetings would have been great for my father and I am thankful that there are places for people to get together for this terrible disease, where they can help one another through the ordeal. All the best to you and your meetings and I am sorry to be the bearer of the bad news.

Truly Kevin Davidson

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