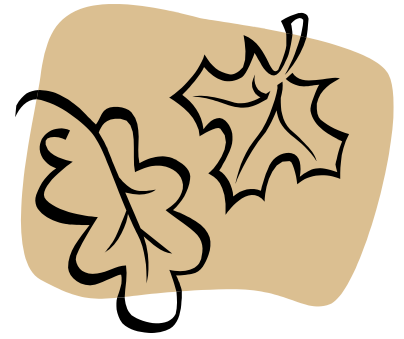


# Canada TN Association Newsletter

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Fall 2010  
November



Greetings all. I hope this newsletter finds you enjoying the fall and looking forward to the Christmas shopping we'll all be doing in a very short time.

I am changing the format of this newsletter a bit – hopefully make it more about you and the other members of your support group and the people scattered across Canada who live in a location with no formal meetings.

Please let me know what you would like to see included in this newsletter – or even if you think this newsletter is worth the time and effort it takes to produce it. Do you want to see it continue? What should it include?



Don't forget to let us know if you change your address, email, or phone number

*Jan*

## *Facial Pain*

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Each time someone has difficulty getting a diagnosis we all have a tendency to think the doctors don't know how to diagnose TN or they, as I have heard often, "just don't know anything." It is easy to be frustrated and critical looking back at months and sometimes even years of struggling with pain that is not identified or managed properly.

In all fairness to the many doctors and dentists out there, TN is sometimes not that easy to diagnose. People are not always able to relate their stories in a clear manner or the symptoms just don't follow the text book. There are 153 conditions listed as causing facial pain on [www.wrongdiagnosis.com](http://www.wrongdiagnosis.com). That means your doctor must eliminate 152 options to come up with a diagnosis of Trigeminal Neuralgia. The actual list of the 153 conditions goes from A (Acoustic Neuroma – a tumor on the 8<sup>th</sup> Cranial Nerve) to Z (Zygomycosis – a very rare fungal infection).

Many patients themselves think the early symptoms of TN are dental in nature. The pain often feels similar to the pain one feels from a deep decay or an abscessing tooth. Often times the dentist is the first professional approached and given his training will naturally look for dental causes for the pain.

There are some standard questions you can expect to be asked by your Doctor during his/her history taking when you discuss facial pain. If you find it difficult to remember everything, writing down the answers to these questions and taking them with you to the Doctor's office could be helpful.

1. Is the facial pain constant or intermittent?

Why: intermittent pain may suggest trigeminal neuralgia, cluster headaches, or atypical migraine. Constant pain would suggest any local abnormality in the structures underlying the face such as an abscessed sinus, an abscessed tooth, or a neoplasm in these areas.

2. Where exactly do you experience the pain?

Why: pain over the side of the face (trigeminal area) may suggest trigeminal neuralgia; Glossopharyngeal neuralgia causes pain in the back of the throat and around the tonsils; sphenoidal or ethmoidal sinusitis causes a constant pain behind the eye or behind the nose; temporomandibular joint dysfunction pain is felt over the joint.

3. Does the pain radiate to anywhere?

Why: impacted wisdom teeth may cause pain localized to the lower jaw and radiate to the ear; temporomandibular joint pain may radiate from the joint to the ear, lower jaw, and forward to the cheek and even the neck;

4. How would you explain the nature of the facial pain?

Why: lightning or electrical shock quality of pain suggests neuralgia; herpes zoster pain may be burning and have an abnormal increased sensitivity to touch; facial migraine is dull and throbbing.

5. What aggravates the pain? Does anything relieve the pain?

Why: pain increased by chewing often suggests being related to the temporomandibular joint, but it could be related to trigeminal neuralgia, dental caries or salivary gland stones; trigeminal neuralgia pain may be aggravated by talking, chewing, touching certain trigger areas on the face, cold weather or wind or turning onto pillow; glossopharyngeal neuralgia may be triggered by swallowing, coughing and talking; cluster headaches may be aggravated by alcohol.

6. Is there a history of facial trauma or surgery?

Why: may explain the facial pain.

7. Is there a history of fever, a rash?

Why: it could indicate an infection.

Many people also find it useful to keep a diary of the pain so that they can provide that information to their doctor. In the diary be sure to include note of the trigger for the pain if you have one and also what gives relief. If you can share your story with others please send it to me.

## *Calgary*

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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.

At the August meeting the Calgary group was joined by Dr. Zelma Kiss and one of her summer students who gave an excellent presentation on TN. They both answered questions from the group. Then the group was asked to complete a questionnaire about their TN experience to

assist with a project the student was doing. The information from the project will also be used in a bigger project down the road in collaboration with the University of Sydney in Australia.

Dr. Kiss is still looking for families with more than one person with TN. Currently she has three families who will undergo genetic testing to see if there is a genetic influence on TN. If you have someone else in your family who also has TN and would be willing to participate in this research, please contact Dr. Kiss at the University of Calgary.

### **Calgary Group updates:**

**John** sends his greetings to everyone. His lung cancer has spread to his pancreas. He is now facing more chemo and possible radiation. He sends his thanks to everyone for their prayers and support and plans to attend meetings when he can.

**Mary** had her MVD in June and is doing great. No pain and no drugs.

**Gaye** had her second MVD this spring. First one was in Calgary 4 years ago and 2<sup>nd</sup> one in Winnipeg. She has some minor "jabs" but not serious enough to need drugs at this time.

## *Niagara Region*

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Please contact Brenda for details on the location and date of the next meeting. Contact her at [Niagara@catna.ca](mailto:Niagara@catna.ca).

## *Regina*

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Meetings are held monthly at the Wascana Rehabilitation Center, 2180 - 28th Avenue, 2nd Floor, Rooms 1, 2, & 3. Contact Faye for specific details. The next meetings are Nov. 13, Dec. 4 at 10 a.m.

From Faye: I have a questionnaire of 22 questions that you can answer with a yes or no that can be taken with you to your Doctor's appointment or to the emergency room so that if it is difficult to talk the information is there. It is also a great diagnostic form. We also have forms that you can fill out with your history like meds you have taken, Doctor's names, etc. E-mail me at [regina@catna.ca](mailto:regina@catna.ca) or phone at 751-0761 if you would like to have a form.

Remember we also have DVDs and books that you can borrow from the Regina Support Group. I will be placing another order for the book "Striking Back". I will order 10 copies. Let me know if you would like a copy.

See you at the next meeting. Faye Meyer, Support Group Leader

### **Updates from Regina**

Best wishes to Susan. Susan had an MVD two years ago in Winnipeg. The pain returned this summer and in late October she returned to Winnipeg for a Glycerol Rhizotomy. We all hope this takes care of the problem. Please let us know.

Here is a bumper sticker for people on Tegretol:



## *Toronto*

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

From Kathy and Sandra: Thank you to all the members of the Toronto group who attend meetings on a regular basis to help inform and support new members. Your compassion in helping others is greatly appreciated. You have supported both of us who have not had good success from surgery. You have deeply touched our hearts with your success and continued support. I'm not sure what we are doing right but we need to continue doing it because we are reaching more new TN patients every day. Thank you. Kathy and Sandra

If there is anyone in the Ottawa area that has TN, I have a patient who would like to connect with you. Please contact Kathy Somers at [kathleen\\_somers248@hotmail.com](mailto:kathleen_somers248@hotmail.com) thank you

## *A TN Story*

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This one came via e-mail:

Hi, I am a 50-year old woman living in Calgary. After 4 years of intermittent inexplicable pain this weekend it totally went off the rails, I am beside myself with constant debilitating pain. Can't sleep, can't talk, can't eat, went to a walk-in clinic yesterday and the doc said - hasn't anyone told you that you have trigeminal neuralgia? So I've started on Tegretol but no effect yet, it's only been 24 hrs. Did some searching on the net and your forum came up. If I'm going to learn to live with this I need help! Wanted to introduce myself and hope I can make contact with a Calgary group. Thanks for being there... M.

Jan: The Tegretol you have started should start to work within a few days. You should notice a gradual decrease in the pain as your blood levels of Tegretol increase. It is a powerful drug which is why you were probably advised to start slowly taking 100mg one or twice a day and then to increase by 100mg a day every 2 or 3 days until you either have reached 800 mg a day or are pain free. That is the normal routine for this drug.

I can put you in touch with a few people in Calgary who can talk to you

M . . . Thanks - I just really needed to hear that there are others out there. The Tegretol is starting to dull the pain a bit, but I just washed my hair and the hot water set everything off again. And of course the crying doesn't help... Would love to meet a support group

Jan: I'm glad the Tegretol is starting to work. You need the break. It does get better and there are options out there for long term good control of the pain. You do not need to suffer without any kind of help.

More than half the people with TN manage by taking drugs like Tegretol. Others decide to go the surgical route. There are choices there too.

As far as a Calgary group, they meet the third Tuesday of each month at 1 pm at the Confederation Park Seniors center. You are welcome to just show up - or you can contact Bev or Phoebe at [calgary@catna.ca](mailto:calgary@catna.ca).

## Letters

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### Neurologist Seeking Patients for Study Stopping TN Pain With Diet

A neurologist on staff at a metropolitan hospital in Detroit in the U.S. is sufficiently impressed with the success of the new low saturated fat diet in stopping typical TN pain that he has volunteered his time to do a study. This study will document the success that already over 40 patients have had for publication in a medical journal. It's not necessary to enrol in the study. Simply try the diet, and answer a few questions by email.

Send your name and P. O. mailing address to ([frank@sokolitz.com](mailto:frank@sokolitz.com)) for a free copy of a 10-page report that includes diet instructions, recipes, and the saturated fat in 140 foods, testimonials, and related health information. There's no charge for mailing outside the U. S.

Pain will typically be reduced or completely stopped in the first few weeks, but in a month you will know if the diet is effective. A pain free patient with six previous TN surgeries has been free of pain for 13 years without medication. The diet requires restricting saturated fat to a little more than recommend by the American Heart Association and the American Cancer Society. The diet has received support from the TNA Facial Pain Association with articles in their newsletter, a national conference presentation, and patient referrals. I just received this

Email from South Africa:

Dear Sir.

My name is Paul E. I am from South Africa. My wife is a sufferer from TN for 17 years. She has used Trileptal 600 for 10 years. About 6 months ago she had a severe attack and we could not get the pain away . One night she was laying here crying out of disparity. I went on the internet and came on your site and everything made sense to us. We know that dairy products trigger the pain but we didn't know that it was the fat in it. We started immediately to reduce her fat intake. In one week there was an improvement and in two weeks the pain was gone.  
YOU WERE SEND BY GOD

Thank you  
Ever grateful  
PAUL

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