

My name is Kathy Somers. I am a member of the Canadian Trigeminal Neuralgia Association (CaTNA). I share the title of Group Leader for the Toronto/York region chapter with Sandra Arangio. It is the goal of our group to make "Trigeminal Neuralgia" better known in society. Below you will find a description of TN, as you requested. Our support group meets the last Sunday of every month at the Thornhill Community Centre, room 6B 9:30 a.m. (but not in DECEMBER)

We have recently joined forces with an on line group called "TNNME" this is an international group that also has many people who are in terrible pain and we are all working together internationally to bring awareness to tn to help others. October 7th has been declared International Trigeminal Neuralgia day. We are working together to have buildings and bridges all over the world to light up in TEAL on this day. This year October 7th 2015 is dedicated to the children and young people who have TN.

Can you imagine for one minute what it's like to not be able to wash your face, brush your teeth, be passionate about a topic and not participate because you can't speak. I'm not talking about a minute, hour etc. I mean start to speak and be in pain for hours or days and never be able to give your opinion. All Emotions you feel cause more pain. Heat cold, steam from the oven stove top, your dinner plate all set off tn. Drafts, fans, air conditioning any kind of air flow in a room can set off tn. No laughing, or smiling as most times it is impossible to change the expression on your face. No running, no jumping, I don't have time to tell you about bumpy roads if your tn is already bad. TN is isolation, loneliness, loss of friends, and depression. I want so badly to reach others who are in pain and don't know what to do about it. Or perhaps they were told it is all in their mind or some other ailment. Last year I had the privilege to participate in the volunteer fair held at Keswick library. By participating in this project 100 people went home knowing what TN is and I received 4 emails from people who have TN and wanted more information.

TN is one of the worse pains known to mankind. Although, there are many medications, and surgeries that TN patients can take, they can be quite unsuccessful for some of us. Sandra and I both have type 1 & 2. We have all the pains described below in all branches on the right side of our face. Sandra's surgery was not successful as she is now classified as Idiopathic pain (means they don't know what it is caused by). My surgery was successful for my type 1, but not type 2 leaving me with pain most of the time with some good stages. But when it returns it is worse than the last time. The medication we take is antiseizure medication that works best for TN and causes terrible side effects. Some people are very allergic to the medication and have no choice but resort to surgery. And although it helps control the pain, we are still in terrible pain daily. 15% percent of MS patients will develop TN.

WHAT IS TRIGEMINAL NEURALGIA

Trigeminal Neuralgia, also known as tic douloureux, is an excruciating facial pain that tends to come and go in sudden shock-like attacks. It is a chronic disorder of the trigeminal nerve (5th cranial nerve), which is the largest of the body's 12 pairs of cranial nerves. The trigeminal nerve has three branches, which conduct sensation from the upper, middle and lower portions of the face, and also the oral cavity, to the brain.

Upper – 1st Branch – Ophthalmic, Eye, eyebrow, forehead and frontal portion of the scalp.

Middle- 2nd Branch – Maxillary, Upper lip, upper teeth, upper gum, cheek, lower eyelid and side of the nose.

Lower- 3rd Branch – Mandibular. Lower lip, lower teeth, lower gum and side of the tongue. Also covers a narrow area that extends from the lower jaw in front of the ear to the side of the head.

The painful attacks of TN can involve one or more branches. Most commonly the middle branch or the lower branch either individually or in combination with each other are involved. Only about 4% of patients experience pain in the upper branch. In rare instances all three branches may be involved. The right side of the face is more frequently affected than the left. In a small percentage of patients, pain occurs on both sides of the face, but rarely at the same time. The area of the nerve branch involvement determines the type of symptoms the patient will describe to the physician. It is extremely important that the patient gives a clear description of the area where the

pain is being felt and the character of the sensation constant, jabbing, shock-like, burning etc. as this will help to confirm the diagnosis and recommendation for treatment.

Since the largest percent of patients have involvement of the middle and lower branches many of the initial symptoms are felt in the teeth and gums. Many patients experience a dull, continuous aching and gum sensitivity to heat and cold prior to the onset of the more intense, classical symptoms of TN. This period, sometimes referred to as pre-trigeminal neuralgia, presents a considerable diagnostic challenge, especially for the dentist since this is, quite often, the first health professional to see the patient. While true dental abnormalities do produce pain, the pain of TN is not caused by dental problems. What may appear, as a toothache may actually be an early symptom of TN. It is not unusual for a TN patient to see half a dozen or more dentists, oral surgeons, ear, nose and throat and TMJ specialists, etc. many modes of treatment - root canals, extractions oral surgeries, etc. – are pursued, to no avail, while the pain steadily worsens and more classic symptoms of TN develop.

I have attached our CaTNA flyer and our TNNME flyer. See www.tnnme.com for more TN stories and information and the buildings and bridges around the world that will light up TEAL for us on October 7th, 2015

WEBSITES OF INTEREST

http://www.umanitoba.ca/cranial_nerves

www.tna-support.org

www.tnnme.com

www.catna2.ca

'TOGETHER WE WILL END THE PAIN'

Our Light Up Teal Request for International Trigeminal Neuralgia Awareness Day.

Hello,

We're celebrating the Third Annual International Trigeminal Neuralgia Awareness Day on October 7th 2015

This year we're focus on awareness for our children and teenagers living with TN and Facial Pain Disorders

What is trigeminal neuralgia?

We would be thankful for your authorization to be able to "Light Up Teal" (or even near to it) on October 7th 2015. If you're not the main one to make this kind of authorization could you please forward this request towards the individual that provides this sort of permissions?

We are sending out the request early to give notice and time for the approval process to accommodate the "Light up Teal" for international bridges, buildings and structures which are taking part. All approvals will be mentioned on this web sites, social network sites as well as continuous press announcements, newspapers articles and/or blog posts.

We will make sure to send any coverage to help keep everyone posted.

We have mentioned the "Light Up Teal" regarding 2014 on this TNnME web site: <http://www.tnnme.com/2014-light-up-teal.html> and once we have your authorization for 2015 we will make sure they outlined on TNnME web site as well.

See below for details however please let me know should there be anything we could do to get your authorization and support...Thank you so much,Toni Saunders

Name of Organization: TNNME = (Trigeminal Neuralgia and Me) as well as (Non Profit) The Facial Pain Research Foundation

International Awareness: Education and Financing for Trigeminal Neuralgia and Facial Pains Disorders

Contact Person: Toni Saunders

Phone number: 617-619-1238

Email address: tawareness@gmail.com

Reason related to submitting the illumination request: Third International Trigeminal Neuralgia Awareness Day October 7th 2015

Web site address: <http://www.tnnme.com>

If you would like to support Canada TNA you can become a member for \$10 per year. This money helps with mailing costs, establishing new support groups and maintaining the web site. We appreciate your support.

Please send this form along with a check or money order to:

Canada TNA
Jan Williams
www.catna2.ca or Kathy Somers

Name: _____

Address: _____

Home Phone: _____

E-mail: _____

Annual Membership fees \$10.00

Donations can be accepted by the local support group. Unfortunately, income receipts are not available at this time

Contact Information

c/o jan williams
help@catna2.ca
Toronto@catna2.ca

Ontario

Niagara Region niagara@catna2.ca
Brenda (905) 937-6178

Toronto toronto@catna2.ca
Kathy (905) 853-9849
Sandra (905) 284-9215

*Patient Support
and Information*

Canada's Trigeminal Neuralgia Association

Together we will end the
pain

Ontario

- Focussed radiation with the Gamma Knife or Linac machines.

TN can also be controlled by drugs. The drugs used are anticonvulsant drugs such as Carbamazepine, Oxycarbazepine, Gabapentin, Pregabalin or Phenytoin.

Trigeminal Neuralgia

Trigeminal Neuralgia is a facial nerve disorder that causes sudden and severe shock-like pains in the face. It is reported to be the most painful condition in the world.

The disease affects approximately 1.5% of the population mostly people over the age of 55 although it can affect people of any age.

There are several causes of TN. It is believed that in most people the disease is caused by the irritation of a blood vessel lying close to the nerve. Other causes include MS, tumors, infections and damage to the trigeminal nerve.

Most people can be helped and successfully treated by either drugs or by neurosurgery. There are three main kinds of surgery:

- The Microvascular decompression which protects the nerve by separating the offending blood vessel from the Trigeminal nerve
- Destructive procedures that damage the nerve to interrupt pain signals. These include the radiofrequency, glycerol and balloon Rhizotomies.

Thornhill

No one should be left to suffer alone.

Education

Canada TNA can arrange seminars presented by experts on the diagnosis and treatment of facial pain. These seminars are open to the general public and are free of charge.

Support

The Canadian TNA will provide information through its website which is open to everyone. Check it out at www.catna2.ca.

References

There are two excellent books recommended: Striking Back! The Trigeminal Neuralgia and Face Pain Handbook. Published by the TNA and written by George Weigel and Kenneth F. Casey, M.D.

Insights: The Facts and Stories Behind Trigeminal Neuralgia. Published by TNA and written by Joanna Zakrzewska, M.D.

TNA, 925 Northwest 56th Terrace, Suite C, Gainesville, FL 32605-6402;
Phone: 1 (800) 923.3608.
www.tna-support.org

or

Canada TNA

This is a network of support groups for anyone with Trigeminal Neuralgia and/or facial pain. The goal of the association is to help patients understand their disease better and to help remove the feelings of isolation and hopelessness that many TN sufferers have experienced.

Canada TNA does not recommend treatment nor make referrals to specific Neurosurgeons or Neurologists.

Currently there are support groups in Alberta, BC, Manitoba, Ontario and Saskatchewan.

Ontario Groups

Groups meet monthly to provide an opportunity for members to share their experiences and to discuss various topics related to TN. From time to time guest speakers may be invited to speak. The meetings are open to everyone and are free of charge.

Meetings are held in:
Niagara



The Trigeminal Neuralgia and Face Pain Handbook

By: George Weigel & Kenneth F. Casey, M.D.

The Facial Pain Research Foundation:

www.facingfacialpain.org

TNA Facial Pain Association:

www.fpa-support.org

Trigeminal Neuralgia Association UK

www.tna.org.uk/

Facebook Support / Awareness Groups

www.facebook.com/Oct17thTNawareness

www.facebook.com/groups/53217423526996/

www.facebook.com/groups/infamily4all/

www.facebook.com/groups/2394464747/

Screen Name **tnnme (twitter)**

Website **www.tnnme.com**

Email **tnawareness@gmail.com**

Facebook **facebook.com/tnnme.tn**

Designed By:

Rebecca D. Thorpe (Indiana Awareness Fighter)

Brochure approved by: TNNME

Trigeminal neuralgia symptoms may include one or more of these patterns:

- Occasional twinges of mild pain
- Episodes of severe, shooting or jabbing pain that may feel like an electric shock
- Spontaneous attacks of pain or attacks triggered by things such as touching the face, chewing, speaking and brushing teeth
- Bouts of pain lasting from a few seconds to several seconds
- Episodes of several attacks lasting days, weeks, months or longer — some people have periods when they experience no pain
- Pain in areas supplied by the trigeminal nerve, including the cheek, jaw, teeth, gums, lips, or less often the eye and forehead
- Pain affecting one side of your face at a time
- Pain focused in one spot or spread in a wider pattern
- Attacks becoming more frequent and intense over time

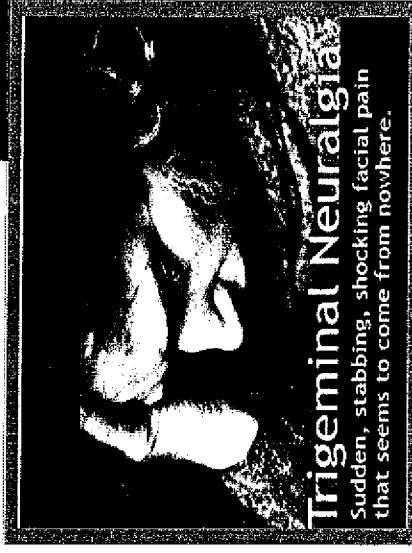
When to see a doctor

If you experience facial pain, particularly prolonged or recurring pain or pain unrelieved by over-the-counter pain relievers, see your doctor.

Could you
have,

Trigeminal Neuralgia?

So painful it's called
"The Suicide Disease"



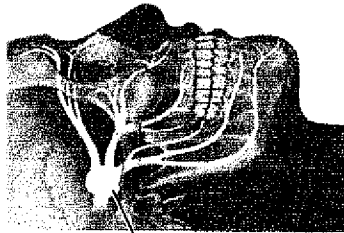
Trigeminal Neuralgia

Sudden, stabbing, shocking facial pain
that seems to come from nowhere.

www.tnnme.com

What is Trigeminal Neuralgia?

Trigeminal neuralgia is a chronic pain condition that affects the trigeminal nerve, which carries sensation from your face to your brain. If you have trigeminal neuralgia, even mild stimulation of your face — such as from brushing your teeth or putting on makeup — may trigger a jolt of excruciating pain.



Trigeminal nerve

You may initially experience short, mild attacks, but trigeminal neuralgia can progress, causing longer, more frequent bouts of searing pain. Trigeminal neuralgia affects women more often than men, and it's more likely to occur in people who are older than 50 although cases occur in people under 40, many are children.

Because of the variety of treatment options available, having TN doesn't necessarily mean you're doomed to a life of pain. Doctors usually can effectively manage trigeminal neuralgia with medications, injections or surgery.

Triggers

A variety of triggers may set off the pain of trigeminal neuralgia, including:

- Shaving
- Stroking your face
- Eating
- Drinking
- Brushing your teeth
- Talking
- Putting on makeup
- Encountering a breeze
- Smiling
- Washing your face

Your facial pain may be caused by many different conditions, so an accurate diagnosis is important. Your doctor may order additional tests to rule out other conditions.

Trigeminal Neuralgia

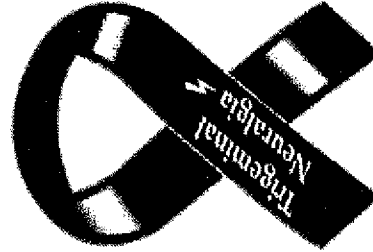
Make an appointment with your family doctor or primary care provider if you have symptoms common to trigeminal neuralgia. After your initial appointment, you may see a doctor trained in the diagnosis and treatment of brain and nervous system conditions (neurologist)

What you can do to prepare

- Write down any symptoms you've been having, and for how long.
- Note the triggers, such as triggers that bring on your attacks of facial pain.
- Make a list of your key medical information, including any other conditions for which you're being treated and the names of any medications, vitamins or supplements you're taking.
- Take a family member or friend along, if possible. Someone who accompanies you may remember something that you missed or forgot.

Write down questions in advance, to ask your doctor at your appointment.

Creating your list of questions in advance can help you make the most of your time with your doctor.



Yearly Awareness Day
October, 7th.