



# Nerve Center

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Periodical Newsletter of the Pacific Northwest TNA Support Group  
Serving the Pacific Northwest Region of Oregon, Washington and Idaho

## Complementary & Alternative Medicine

Our December meeting topic, *Exploring Complimentary and Alternative Medicine (CAM) Therapy* was a subject of great interest to our members based on the good attendance. Most people there had tried some type of CAM therapy and wanted to share their experiences with others about what helped them, what didn't work for them, as well as to learn about new ones. One thing we discovered is that while some members had similar symptoms and diagnoses, they also had differing results from the same CAM treatments. Because of the complexity involved, we will not post patient's individual results here, but will discuss the various CAM therapies available today that could be of benefit to TN and face pain patients.

The National Institute of Health's department called the **National Center for Complimentary and Alternative Medicine**, or NCCAM states that CAM is a group of diverse medical and health care systems, practices and products are not presently considered to be part of conventional medicine. In CAM terms, complimentary medicine is *used together with* conventional medicine, and alternative medicine is *used in place of* conventional treatments. Another term used is that of Integrated Medicine, which involves the use of CAM treatments *along side of* traditional treatments, (offered by the same practitioner or practice group), *and the combined therapy has quality scientific evidence* of safety and effectiveness. According to a NCCAM study, 74.6 % of Americans have tried CAM at least once, and 62.1% had used CAM in the prior 12 months. (Data is from 2002) The statistics include patients who used mega-vitamin therapy and prayers, but when those are excluded the percentage of Americans who have ever used CAM falls to just under 50%. Unfortunately, of those patients who use CAM, less than half will tell their conventional doctors about it. (Continued on page 2)

## 6<sup>th</sup> National TNA Conference in Portland!

September 14 – 16<sup>th</sup> will be the dates of the National TNA Conference coming to Portland. Our group is planning to welcome the hundreds of attendees who will visit our city, and help the national TNA organization in many ways. Please contact Ruth Purchase if you can help in any of the following areas: Volunteer time during the convention, donate goods or services for the silent auction or provide a room for out-of-town TNA members.

## April 1<sup>st</sup> Meeting: TN is Not for Fools!

“Don't Be Fooled - Deal with It!” Will be the topic of our meeting on Saturday April 1<sup>st</sup>, at 1:00 pm, at Legacy Meridian Park Hospital in Tualatin, Or. We will learn how TN and related face pain shapes our psychological and social well-being, and how ignoring those changes can be a foolish move on our part. We will address issues that affect us all, utilizing a step-by-step approach to understanding how pain impacts our lives and how we can change that influence for the better. Discussions will focus on ways to minimize the effect of debilitating pain in our relationships, social life, career, and self-esteem.

There will be a special program to address the needs of our family and friends as caregivers. They will learn from others who are in similar circumstances as they explore how pain can interrupt their household and relationships, and how they can adjust. With guidance and insight, patients and caregivers alike will learn how change can be a positive move towards a more dynamic life and a deeper appreciation of close relationships. Don't miss out – we'll see you on April Fools Day! (See map on back to meeting location)

## What is Meant by “Related” Facial Pain?

The end of January brought out several new members who were intrigued by the topic of our meeting, *The Trigeminal Nerve and Related Facial Pains*. When new face pain patients begin to research their symptoms, many find that they fall into one of the categories TNA refers to as “related” facial pain. (Sometimes referred to as “atypical” face pain.) Unlike typical trigeminal neuralgia, where MRI's and clear-cut symptoms help with the diagnosis, the symptoms of the TN related disorders are varied, leaving the patient and doctors with a wide range of diagnoses to look into. At the meeting, detailed medical illustrations were passed around that showed the trigeminal nerve in multiple layers of the facial tissues. It was very enlightening to the newer members to see and understand the complexity of the nerve and how deep and wide-ranging the fine endings of the trigeminal nerve's branches reach into the face and head.

To understand more about the “related” nerve disorders, we need to learn more about the cranial nerves and the terminology used to describe different types of nerve pain. (Continued on page 2)

## **Exploring CAM (Continued from p.1)**

While some CAM therapies have abundant scientific evidence regarding their effectiveness, others have been more problematic to study. One of the primary reasons for a lack of studies is economic. Very few CAM products or protocols can be protected by a patent, so there is no way for commercial entities to protect their investments in the research. It is also difficult to conduct studies in this field as the outcome measures are hard to quantify because results are subjective due to the applications of certain CAM therapies being highly specific to the patient and to the practitioners who have variable approaches to the same treatment. Double-blind or placebo studies, (a standard in scientific research), may not be applicable to many CAM therapies. In many cases there is no way to have the doctor create a "sham" treatment that would not be noticed by the patient, and therefore the patient's reporting could be subject to that influence. With traditional medical studies a patient could be taking a placebo instead of a medication and never know the difference, making the test results reliable and scientifically reproducible. In many types of CAM treatments, the desired outcomes are supposed to be subjective to the individual and to their relationship with the practitioner, as in prayer, meditation, energy healing, balancing Qi, etc... Since those results are not able to be duplicated, they fly in the face of conventional scientific study parameters. However, anecdotal evidence from patients themselves is the standard by which many CAM treatments are to be evaluated. (If the patient feels better due to the therapy.) NCCAM is making some progress by putting together scientists who wish to study CAM with those who practice it, and to help them with study guidelines and funding. Many therapies that started out as strictly CAM treatments have now found their way to conventional medicine as they have been able to scientifically substantiate their claims, such as the use of TENS units for healing and pain, light therapy for depression, and botanicals that are used in prescription medications.

NCCAM has set up 5 main categories of CAM therapies. The first category of whole medical systems encompasses most other therapies listed. Some treatments also stand alone in the patient's view or within the parameters of the health care provider's practice.

**Whole medical systems** are built upon complete systems of theory and practice. Often, these systems have evolved apart from and earlier than the conventional medical approach used in the United States. Whole medical systems involve complete systems of theory and practice that have evolved independently from or parallel to conventional medicine. Many are traditional systems of medicine that are practiced by individual cultures throughout the world. Major Eastern whole medical systems include traditional Chinese medicine (TCM) and Ayurvedic medicine, one of India's traditional systems of medicine. Major Western whole medical systems include homeopathy and naturopathy. Other systems have been developed by Native

American, African, Middle Eastern, Tibetan, and Central and South American cultures. While whole medical systems differ in their philosophical approaches to the prevention and treatment of disease, they share a number of common elements. These systems are based on the belief that one's body has the power to heal itself. Healing often involves marshalling multiple techniques that involve the mind, body, and spirit. Treatment is often individualized and dependent on the presenting symptoms.

In the *Traditional Chinese Medicine* view, the body is a delicate balance of two opposing and inseparable forces: yin and yang. Yin represents the cold, slow, or passive principle, while yang represents the hot, excited, or active principle. Among the major assumptions in TCM are that health is achieved by maintaining the body in a "balanced state" and that disease is due to an internal imbalance of yin and yang. This imbalance leads to blockage in the flow of Qi (or vital energy) and of blood along pathways known as meridians. TCM practitioners typically use herbs, acupuncture, and massage to help unblock Qi and blood in patients in an attempt to bring the body back into harmony and wellness.

*Ayurveda*, which literally means "the science of life," is a natural healing system developed in India. Ayurvedic texts claim that the sages who developed India's original systems of meditation and yoga developed the foundations of this medical system. It is a comprehensive system of medicine that places equal emphasis on the body, mind, and spirit, and strives to restore the innate harmony of the individual. Some of the primary Ayurvedic treatments include diet, exercise, meditation, herbs, massage, exposure to sunlight, and controlled breathing.

*Naturopathy* is a system of healing, originating from Europe, that views disease as a manifestation of alterations in the processes by which the body naturally heals itself. It emphasizes health restoration as well as disease treatment. The term "naturopathy" literally translates as "nature disease." The core modalities supporting the naturopathy principles include diet modification and nutritional supplements, herbal medicine, acupuncture and Chinese medicine, hydrotherapy, massage and joint manipulation, and lifestyle counseling. It emphasizes the doctor as teacher, and the treatment of the "whole person".

(Continued on p. 4)



## **Related Facial Pain (continued from p. 1)**

**There are 12 pairs of cranial nerves** in the head that begin in the brainstem, one on each side. Here is a brief list of the cranial nerves and the areas they control.

V-I Olfactory (smell)

V-II Optic (vision)

V-III Oculomotor (movement of eyes and focusing)

I-V Trochlear (movement of eyes)

- V Trigeminal V-I upper branch, V-II middle branch, V-III lower branch (sensation in face, jaw muscles used in chewing)
- V-I Abducens (movement of eyes)
- V-II Facial (facial muscles, scalp, taste)
- V-III Acoustic or Vestibulocochlear (hearing, balance)
- I-X Glossopharyngeal (taste, swallowing, sensation in pharynx and middle ear)
- X Vagal (movement and sensation in pharynx and larynx, sensation in abdominal organs, heart rate, blood pressure, digestion)
- X-I Accessory (muscles in pharynx, larynx, upper neck and throat)
- X-II Hypoglossal (movement of tongue)

**Common terms describing nerve pain** are used incorrectly by patients at times. To make it clearer when communicating with your health care providers, it is helpful to learn what those term mean.

### **neuralgia**

Pronunciation: n(y)û-<sup>1</sup>ral-jə

: acute paroxysmal pain radiating along the course of one or more nerves usually without demonstrable changes in the nerve structure

### **neuritis**

Pronunciation: n(y)û-<sup>1</sup>rīt-əs

: an inflammatory or degenerative lesion of a nerve marked especially by pain, sensory disturbances, and impaired or lost reflexes

### **neuropathy**

Pronunciation: n(y)û-<sup>1</sup>rəp-ə-thē

: an abnormal and usually degenerative state of the nervous system or nerves; *also* : a systemic condition (as muscular atrophy) that stems from a neuropathy

### **neuropathic**

Pronunciation: n(y)ûr-ə-<sup>1</sup>path-ik

: of, relating to, characterized by, or being a neuropathy <neuropathic pain> <neuropathic disorders>

### **paroxysm**

Pronunciation: <sup>1</sup>par-ək-<sup>1</sup>siz-əm *also* pə-<sup>1</sup>räk-

Function: *noun*

**1** : a sudden attack or spasm (as of a disease)

**2** : a sudden recurrence of symptoms or an intensification of existing symptoms

### **paroxysmal**

Pronunciation: <sup>1</sup>par-ək-<sup>1</sup>siz-məl *also* pə-<sup>1</sup>räk-

räkFunction: *adjective*

: of, relating to, or marked by paroxysms.

**Cranial nerves that are involved in pain states** can mimic TN, and often the treatments use similar drugs and surgical procedures. *Glossopharyngeal Neuralgia* has the same shock-like pain of TN, but it centers in the tonsils, pharynx and base of the tongue. The pain can also radiate along the angle of the jaw, the ear, and upper lateral neck. It can also have an effect on the heart rate and blood pressure because of the proximity to the vagal nerve. *Nervus Intermedius* or *Geniculate Neuralgia* involves the somatic sensory branch

of the facial nerve, and has also been described as being an independent cranial nerve that lies between the facial and acoustic cranial nerves, (hence the name intermedius). The pain symptoms are sharp stabbing and shock-like pains deep within the ear. Stimulation by sound, swallowing or talking causes the episodic pain, sometimes with bitter tastes, tinnitus and vertigo during attacks. Although it can originate from a neuro-vascular compression like TN does, it has also been found to originate from herpes zoster inside the ear canal in some patients. *Vegal and Superior Laryngeal Neuralgia* symptoms are paroxysms of pain in the side of the thyroid cartilage, the pyriform sinus, angle of the jaw and rarely in the ear. Occasionally the pain radiates up into the jaw. It is similar to TN pain except for the location. The combination of glossopharyngeal and vegal as well as trigeminal pain has been reported. *Occipital Neuralgia* has symptoms of pain in the back of the head and upper neck. It can be continuous and throbbing with shock-like pains that may be superimposed. The pain is not easily triggered, but pressure over the occipital region can lead to episodes. True occipital neuralgia is different than tension headaches, which are often described as a headache in the back of the head. The occipital nerve originates from the 2<sup>nd</sup> - 3<sup>rd</sup> cervical area, and is not considered a cranial nerve. Treatment can vary as it does with trigeminal nerve disorders, from surgically relieving a compressed nerve to anti-convulsants and other medications.

In addition to the cranial nerve neuralgias listed above, several other diagnoses can mimic trigeminal nerve pain. Although there are too many to list here, we will give some brief descriptions of the clues to possible diagnoses from the ***Striking Back! Trigeminal Neuralgia and Face Pain Handbook***.

This list can help facilitate conversations between patients and physicians, giving them alternative areas to look into. Symptoms are listed first - *a possible diagnosis second*.

Pain in the side of head, tender temple, blurred vision? – *Temporal arteritis*.

Throbbing pain in side of head, temple tender? – *Migraine or paroxysmal hemicrania*.

Dull, aching, constant pain on both sides of face? – *Sinusitis*

Dull, aching, fleeting pain on both sides of face? – *Periodontal pain or vascular orofacial pain*

Variable pain that moves around face? – *Atypical facial pain or trigeminal neuropathy*

One-sided pain affecting teeth or mouth only? – *Odontalgia or pulpitis or myofascial pain or temporomandibular joint disorder or neuralgia-inducing cavitational osteonecrosis (NICO) or cracked tooth*.

One-sided pain affecting eye and forehead? – *Tolosa-Hunt syndrome or orbital myositis or Raeder's paratrigeminal syndrome*.

One-sided pain affecting eye and forehead with facial flushing and tearing? –

*Short-lasting unilateral neuralgiaform headaches with conjunctival injection and tearing, (SUNCT) or cluster headaches.*

Sharp, stabbing, one-sided pain? –

*TN type 1 or Lyme disease*

Aching, stabbing, one-sided pain? -

*TN type 2 or symptomatic TN.*

One-sided pain with crusting lesions? -

*Post-herpetic neuralgia.*

Burning one-sided pain with numbness? –

*Trigeminal neuropathy or deafferentation pain or trigeminal neuritis or anesthesia dolorosa, (AD)*

While still very rare, facial pain can also be caused by tumors or multiple sclerosis. Most experts agree that patients should be given a MRI to rule out these abnormalities when they present with unusual facial pain. None of the descriptions above replace a careful history and examination by a qualified doctor. To aid their physicians in finding a diagnosis, patients are encouraged to keep a short journal with their pain levels and symptoms along with a timeline, and note any triggers that may set off the pain. They should keep track of all treatments and medications tried and whether or not they helped the pain. With diligence and perseverance by patients and doctors alike, even the most unusual face pain conditions can be properly diagnosed and treated with success.



### **Exploring CAM (Con. from p. 2)**

*Homeopathy* is a complete system of medical theory and practice. Its founder, a German physician hypothesized that one can select therapies on the basis of how closely symptoms produced by a remedy match the symptoms of the patient's disease. He called this the "principle of similars." He proceeded to give repeated doses of many common remedies to healthy volunteers and carefully record the symptoms they produced. This procedure is called a "proving" or, in modern homeopathy, a "human pathogenic trial." As a result of this experience, he developed treatments for sick patients by matching the symptoms produced by a drug to symptoms in sick patients. Homeopathy emphasizes carefully examining all aspects of a person's health status, including emotional and mental states, and tiny idiosyncratic characteristics.

***Biologically based practices*** use substances found in nature, such as herbs, special diets, or vitamins, (in doses outside those used in conventional medicine). Biologically-based therapies include, but are not limited to, botanicals, animal-derived extracts, vitamins, minerals, fatty acids, amino acids, proteins, prebiotics and probiotics, whole diets, and functional foods. Dietary supplements are a subset of this CAM domain. Many of the biological therapies today have a foundation in 1000's of years of application by native populations throughout the world. By the Middle Ages, thousands of botanical products had been inventoried for their medicinal effects. Some, like digitalis and quinine, form the basis of modern drugs. Functional foods include

examples such as soy, nuts, seeds, blueberries, and cranberries, which have documented benefits.

***Energy medicine*** involves the use of energy fields, such as magnetic fields or biofields (energy fields that some believe surround and penetrate the human body). Energy medicine is a domain in CAM that deals with energy fields of two types: Veritable, which can be measured and Putative, which have yet to be measured. Energy therapies involve the application of electrical and magnetic energy fields along with other energy forms that have yet to be measured by traditional standards. There are many well-established uses for measurable energy fields to diagnose and treat disease in traditional medicine, such as; electromagnetic fields used in MRI's and similar imaging techniques, pacemakers, electrical stimulation, radiation treatments, UV lights and lasers. CAM treatments utilizing energy medicine usually include putative energy forms, (although there are controversial claims that some of these energy forms can now be measured). Therapies involving putative energy fields are based on the concept that human beings are infused with a subtle form of energy. This vital energy or life force is known under different names in different cultures, such as Qi in traditional Chinese medicine. Herbal medicine, acupuncture, acupressure, moxibustion, and cupping, for example, are all believed to act by correcting imbalances in the internal biofield, such as by restoring the flow of Qi through meridians to reinstate health. Some therapists are believed to emit or transmit the vital energy to a recipient to restore health. CAM therapies may include; pulsating electrotherapy, low millimeter wave therapies, light therapy for seasonal affective disorders, energy healing, acupuncture, Qi Gong, therapeutic touch, static magnets, and distance healing such as intercessory prayers.

***Manipulative and body-based practices*** are based on manipulation or movement of one or more body parts. Under the umbrella of manipulative and body-based practices is a diverse group of CAM interventions and therapies. These include chiropractic and osteopathic manipulation, massage therapy, acupressure, reflexology, rolfing, Bowen technique, Trager bodywork, Alexander technique, Feldenkrais method, and a host of others.

Manipulative and body-based practices focus primarily on the structures and systems of the body, including the bones and joints, the soft tissues, and the circulatory and lymphatic systems. Although many providers have formal training in the anatomy and physiology of humans, there is considerable variation in the training and the approaches of these providers both across and within modalities.

Manipulative and body-based practices share some common characteristics, such as the principles that the human body is self-regulating, has the ability to heal itself, and all parts of the human body are interdependent. Practitioners in all these therapies also tend to tailor their treatments to the specific needs of each patient.

**Mind-body medicine** uses a variety of techniques designed to enhance the mind's ability to affect bodily function and symptoms. Mind-body medicine focuses on the interactions among the brain, mind, body, and behavior, and the powerful ways in which emotional, mental, social, spiritual, and behavioral factors can directly affect health. It regards as fundamental an approach that respects and enhances each person's capacity for self-knowledge and self-care, and it emphasizes techniques that are grounded in this approach. Mind-body medicine typically focuses on intervention strategies that are thought to promote health, such as relaxation, hypnosis, visual imagery, meditation, yoga, biofeedback, Tai Chi, Qi gong, cognitive-behavioral therapies, group support, autogenic training, and spirituality. The field views illness as an opportunity for personal growth and transformation, and health care providers as catalysts and guides in this process.

**CAM therapies of all types** can be controversial, and the patient needs to be aware of the benefits and risks associated with them. Traditional medical doctors and researchers are often skeptical of the claims made by CAM patients and providers, and indeed many have seen the untoward effects of delayed traditional treatments or unconventional ones that didn't work. The public needs to be protected as there are many quality control problems with labeling and standardization among dietary treatments, herbal medicine and supplements. Likewise, there needs to be a way to document and study the positive effects of CAM treatments on patients so that that data can be shared without loss of time and the undue cost of duplicating research efforts. Doctors of both traditional and alternative medicine need to be open to new evidence, either positive or negative regarding the use of CAM.

**The lesson for the patient** is to proceed with the utmost amount of information at their hands and to use common sense when dealing with a CAM therapy. In the book, **Striking Back! The Trigeminal and Face Pain Handbook**, there are several tips on CAM shopping. The first thing listed is to *do your homework*. While there are many books and literature available on the subject, keep in mind that most of it is based on advocates for a particular therapy. The NCCAM division of the NIH has resources available to check up on CAM treatments & research and to look for herbal supplement information or warnings, online at [www.nccam.nih.gov](http://www.nccam.nih.gov), toll free number, 1-888-644-6226, or you can write to the NCCAM Clearing house, PO Box 82189 Silver Spring, MD 20907-8218. **Research prospective practitioners** by asking about their experience, training, license or certification and any professional organizations they belong to – and then check on it. **Get first hand referrals** from the practitioner and from face pain patients and others who have good experiences with local CAM practitioners. **Get details about the proposed therapy** such as what will be done, how long will it take, and if it will have effects that could interfere with your traditional treatments. If you don't understand something, ask – and

don't be swayed by anything that doesn't sound reasonable to you. **Find out about safety and effectiveness** by asking the practitioner about any risks, what is the track record of success, and then look to other resources to get solid information on the therapy. **Get a prognosis** by asking the therapist what results you should expect, how you will know if it is working, and how long it will take. **Ask about costs**, how much, how often will you need it, if insurance will cover it and if you will need to purchase anything else? **Keep your primary care doctor informed**. Any and all therapies must be reported, even over-the-counter vitamins or remedies, manipulative therapies, etc... Your doctor may be open to integrated medicine and refer you to other CAM therapies that could be helpful. **Evaluate the first session**. Are you satisfied with treatment, did it make sense, were you comfortable with the therapist and did they know about face pain? Does the treatment plan seem reasonable?

Facial pain patients recognize CAM treatments as a viable addition to their arsenal of pain relief therapy. By using common sense and researching their options, they can have help with their pain and with their better health overall through the use of CAM therapies. TNA has informational flyers that are available, and there is abundant information in the book, **Striking Back! The Trigeminal Neuralgia and Face Pain Handbook**. Order through your support group or the National TNA office. (See box below)

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