

# Quarterly

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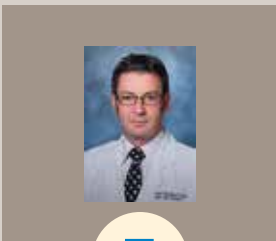




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## From the Chairman of the Board

The mission of TNA – The Facial Pain Association is to provide people who have facial nerve pain disease, and their caregivers, with information and community that helps them to manage their lives. The FPA works to be the global “go to” source for information that is grounded in science and what is known about what works and what doesn’t. This letter is about how science, testing a hypothesis with real data, guides what we do for you at the FPA.

First, the FPA relies on the members of its Medical Advisory Board and other healthcare professionals with recognized expertise. Those professionals, their experience in clinical practice, their research and their publications in refereed and authoritative journals keep us up to date on diagnosis and treatment options for facial nerve pain. The professionals may not always agree, much remains unknown, and that is one of the challenges that the FPA helps people to navigate. The state of the science concerning facial nerve pain shapes the FPA’s conference programs, it leads to articles in the Quarterly, and it grounds our advice when you call our office in Gainesville with questions.

The FPA does not make any diagnosis or recommend any particular treatment. Science shows that what a person experiences as facial nerve pain can have many different and even a combination of causes. Science shows that no one treatment works for every patient every time. Science shows that for those who have certain characteristics and symptoms, some treatments are more likely to be effective than others. Further, some treatments are untested and science shows that others are not effective. Beyond those, few generalizations about facial nerve pain appear to make sense. The most accurate diagnosis and the best treatment plan are case specific. They depend on a person’s physiology, psychology, age, family circumstances and many other factors. Even on that foundation, the results of treatment may be uncertain. It may take several tries to find what works best, and that too may change over time. The FPA works to keep members informed

about the science concerning facial nerve pain so that they can ask the right questions and so that they can provide informative answers to the questions asked by healthcare professionals. Working together, a patient and professional must sift through the potential diagnoses and then decide on a treatment plan.

Much about diagnosis and treatment remains unknown and we keep members informed about new research through the FPA Newswire. Compression of the facial nerve by an artery or vessel appears necessary but not sufficient in many cases, and the underlying causes of pain may be combinations of various genetic and environmental factors. Decompressing or desensitizing a portion of the facial nerve does appear to reduce or eliminate pain in many cases, but that is not always effective. Medications, and other treatments too, are often but not always and forever effective. Work sponsored by the Facial Pain Research Foundation, University of Pittsburgh, Yale University and others may lead to a better understanding of the causes and more effective treatment options in the future. The FPA encourages that research and provides contact information to pain patients who would like to participate.

I must close this letter about science with a sad note about a scientist. Dr. Steven Graff-Radford, DDS died on October 15, 2016 at the young age of 59. Dr. Graff-Radford conducted extensive research, published over 150 articles, taught hundreds of students and he was a long-term member of our MAB with particular expertise in medications for facial nerve pain. He also treated patients at the Cedars-Sinai Pain Center in Los Angeles. For me and many others, it was his human side that touched us most. He understood intense pain, he took our telephone calls, he fit us in to his schedule that day. Thank you Steven, we miss you.



Jeff Bodington, Chairman of the Board  
TNA – The Facial Pain Association



## The MAB Corner



Spotlight on new Medical  
Advisory Board Member

Dr. Harry van Loveren is professor and chair of the Department of Neurosurgery at the University of Florida College of Medicine and the newest member of the FPA Medical Advisory Board.

Prior to USF, he was a partner in the Mayfield Clinic in Cincinnati and faculty neurosurgeon with the University of Cincinnati Department of Neurosurgery for seventeen years working closely with Dr. John Tew on their combined long-standing interest in trigeminal neuralgia.

Dr. van Loveren also focused upon the scientific basis of trigeminal neuralgia during his research in Zurich, Switzerland in the laboratories of Professors Helmut Hass and Jean Sigfried. In addition to a large clinical practice and scientific interest in trigeminal neuralgia the burden of multiple family members with trigeminal neuralgia has provided him with an unfortunate but unique understanding of the suffering associated with this disease.

Born in the Netherlands of a Marine Corps master-sergeant father and an Asian mother, Dr. van Loveren was raised to cherish discipline, hard work

for its own sake, and a quiet response to all important events. His college education was varied, ranging from political science at Holy Cross to Chemistry at the University of Cincinnati (UC), with time off in between to try a traditional family career as a carpenter. Medical school was a late decision.

Since 1982, Dr. van Loveren has contributed over 115 academic papers in various publications. He has also written 36 book chapters, and in 1993, he and his mentor, Dr. John Tew wrote the Atlas of Operative Microneurosurgery, Volume I, Aneurysms and Arteriovenous Malformations, the first-place winner of the Association of Medical Illustrators award for a medical atlas. Dr. van Loveren has lectured at more than 200 conferences across the United States and around the world.

In addition, he has had 17 visiting professorships in seven countries, conducted over 60 practical courses, and organized more than 20 professional symposia. He has mentored 24 skull base fellows and six post-graduate fellows, and has served as an investigator or co-investigator in more than 30 clinical research projects.

Dr. van Loveren enjoys sports such as skydiving, boating, scuba diving, and touring the scenic byways of Florida on his motorcycle. ●



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**QUARTERLY**  
is published four times per year by  
The Facial Pain Association,  
408 W. University Avenue, Suite 402  
Gainesville FL 32601-3248

800-923-3608

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# A Tribute to Steven Graff-Radford, DDS

By Anne Ciemnecki

Sad, tragic, horrible, humbling, shocking . . . These are all reactions to the untimely death of Dr. Steven Graff-Radford, our friend and colleague, on his 59th birthday due to metastatic cancer. For me, the loss was deeply personal. The night I learned of his death, I dreamed I was floating above the earth and could not land. Dr. Graff-Radford had been my anchor. I always knew that no matter what, Dr. Graff-Radford would be there for me. He would be sure that I got an appointment (even on short notice) when business brought me to Los Angeles. He answered his own cell phone when I called. He coordinated care with my east-coast doctor who called him "Little Stevie Wonder." His unique South African accent was a voice of hope and reason. He taught and advocated. There was always a solution up the sleeve of his white coat.

My relationship with Dr. Graff-Radford was love at first citation. In 1992, months after a root canal, I was left with face, tooth, and mouth pain. I was worried because both my mother and grandmother had classic trigeminal neuralgia. But my pain was different and doctors did not know what it was. I bounced between dentists, oral surgeons, endodontists, and ear, nose and throat specialists. It was not sinus related. The root canal was perfect. There were no other tooth problems. Some suggested that it was psychosomatic. One suggested that I "needed" the



*"Facial pain is a complex disorder with many causes and diagnoses. When suffering with facial pain the most important component in management is diagnosis. Too often the wastebasket term "Atypical Facial Pain" is used and if so the patient should challenge the clinician for a clearer diagnosis. It is clear that psychological factors may aggravate facial pain of any cause, but they are not to be blamed as the primary etiology. Once a diagnosis is established, persistence and perseverance in therapy will help the majority of those who suffer."*

— Steven Graff-Radford, DDS

pain to survive. I was told I was "crazy" so often, that I began to believe it myself. One evening when I had an iota of energy, I did a Medline search and was astonished to find: "Is Atypical Odontalgia a Psychological Problem?" Published in peer-review journal, the article explained that standard scores on the Minnesota Multiphasic Personality Inventory Scale for patients with atypical odontalgia (now called pain of idiopathic origin) were within normal ranges. Psychological dysfunction was not a primary condition for people with inexplicable facial pain. The principal investigator and author of the article was Steven Graff-Radford. Who would not be in love with a doctor who was compassionate enough to conduct such research?

**"Graff-Radford" . . . continued on page 6**



***“Graff-Radford”...continued from page 5***

I became an on-line stalker, looking for more and more of Graff-Radford's facial-pain articles. I read every one. During Dr. Graff-Radford's distinguished career as a Clinical Professor at the UCLA School of Dentistry and the director of the Headache, Orofacial Pain and Sleep Apnea Program at the Cedars-Sinai Pain Center, he published more than 150 papers, chapters and abstracts. He completed a life-changing fellowship in pain management at UCLA and blazed a trail for dentists in that field. To recognize his skill, the American Headache Society dedicated an annual lecture entitled: The Steven Graff-Radford Lecture on Headache and Facial Pain. He served on the Medical Advisory Board of the Facial Pain Association. His contributions were profound.

I knew him as so much more than his publications and academic and professional honors. Eleven years after I found the article that proved I was not demented, I was working on a project that brought me to Los Angeles six times in three months. When my pain became unbearable again, I told myself that if I could travel cross-country for

work, I could go for myself. I was face-to-face with “my idol” for less than 10 minutes when he said, “I know what you have and I know how to fix it.” Then he went on to explain that there was likely a compression that an MVD could fix even in the absence of the classic TN1 pain. An MRI proved him correct. He gave me hope that I will never forget.

One of the last things Dr. Graff-Radford did was prepare “A Patient's Guide to Management of Trigeminal Neuropathies and other Facial Pain” for the Facial Pain Association. It appeared in the Fall 2016 issue of *The Quarterly*. The article is informative, comprehensive, and readable. It will guide patients for years to come. He obviously prepared this article while he was dying. Though he missed a few promised delivery dates, he never mentioned his condition. As usual, his patients came first.

We extend our sympathies to his wife Natalie and his daughters Alexa and Kate. Thank you for sharing him. His loss leaves a gap in wise and compassionate care. He was the epitome of what we try to accomplish at the FPA. ●





# Welcome to the New facepain.org

We at the FPA would like to welcome you to our newly redesigned website. We have taken great care to update and improve all of the information on this site. Whether you are a first time user or a regular visitor you will be able to access information faster and easier on desktop or mobile devices. The FPA website offers educational information along with patient stories told via the Video Project and short documentaries featured on the home page. Recorded webinars are easily viewed or you can page through the resources provided in the Quarterly library.

As always, the website is an evolving platform and we will continue to improve and develop the site. In the meantime, please explore..

The image shows a screenshot of the facepain.org website with several callout boxes pointing to specific features:

- Click on LOGO will always take you back to the home page**: Points to the FACIALPAIN ASSOCIATION logo in the top left navigation bar.
- About the Association**: Points to the "Learn More" button under the "The World's Largest Organization" header.
- Access to Facial Pain information**: Points to the "Learn More" button under the "What is Trigeminal Neuralgia?" section.
- Drop down menus provide more information**: Points to the navigation menu in the top right corner.
- Documentary Series directed by Alana McNair, TN patient**: Points to the video player showing a woman in a pharmacy.
- Connect online with other patients**: Points to the "Forum" button in the "Video Project", "Forum", and "Webinars" section.
- Patients talk about their pain triggers**: Points to the "Video Project" button in the same section.
- View past webinars**: Points to the "Webinars" button in the same section.
- Current topics of interest**: Points to the "Latest from Our Blog" section.
- Download the New Patient Guide**: Points to the "Download the New Patient Guide" button in the "The Patient Guide" section.
- Access the FPA Quarterly library**: Points to the "Quarterly Journal" button in the bottom navigation bar.
- Review credentials of professional members**: Points to the "Find A Doctor" button in the bottom navigation bar.

# Optimizing Primary Partner Relationships in the Context of Chronic Facial Pain

By Leesa Morrow, PhD

## About the Author:

Leesa Morrow, PhD is a clinical psychologist with extensive experience working with TN patients. Dr. Morrow is a frequent presenter at FPA conferences.



Pain is both a private experience and a social one. It is undeniably true that the patient has a private experience of pain that cannot be shared. However, the patient's private experience of pain inevitably results in behavioral changes that others can see and this creates the patient's social experience of pain. Once pain has become a social experience, it impacts not only the patient, but also significant others in the patient's life. When pain patients are connected to significant others, as most are, their experience of pain is importantly and unavoidably shared.

All pain behavior has a communicative effect. Wincing, groaning, pained facial expressions, anxiously touching the face, refusing to be touched, interpersonally withdrawing, irritability, inability to participate in household chores or employment, refusal to participate

in activities out of fear of pain, indeed, any pain-related behavior that touches the life of someone in relationship to the patient is, in part, an act of communication. Even when patients are determined not to communicate about their pain – even when they are determined to keep their experience of pain internalized and private – their behavior is unavoidably communicative, as much as any words could be. Significant others cannot help but recognize pain behavior as meaningful. It says something about the status of their partner and this does not typically elicit indifference from a devoted partner.

Complicating things is the fact that pain behavior often includes an unspoken set of expectations of what others will do in response. Sometimes these expectations are unconscious or only partially

conscious. Significant others who witness pain behavior typically perceive expectations in the patient's behavior, even in cases when the patient did not consciously expect anything in response. Sometimes the significant other perceives expectations that are actually derived from their own fear of being inadequate or overwhelmed, although they may not recognize this. The meaning that patients and significant others attach to pain behavior is thus inevitably complex. This is in large part because pain-related communication is typically nonverbal and rarely occurs in the context of full awareness. And, as is often the case, lack of awareness creates problems.

Common unacknowledged pain-related patterns of communication are discussed in this article. The article closes with tips that are intended to facilitate mindful pain-related communication between patients and significant others so that living with chronic facial pain does not degrade important relationships. Focus is placed upon romantic relationships. For the sake of clarity, the person with a facial pain diagnosis is referred to as the patient. Persons in relationship to the patient are referred to as significant others or partners.

It is important to understand, and accept, that pain is not a simple straightforward physiological event. This is not the same thing as saying that the pain is "all in your head," something most patients fear others will assume. Even in the case of trigeminal neuralgia, an undeniably vicious "real" pain, the patient's experience of pain is importantly influenced by its social aspects. As time goes on, the patient's experience of pain, the behavioral changes that the pain brings about, and the reactions of significant others to the patient's pain behavior, influence the patient's private pain experience in very real ways. We know this happens. Researchers have discovered that interpersonal dynamics affect one's tolerance of pain and one's experience of pain intensity apart from the diagnosis that underlies the pain.

For example, research shows that partnered pain patients generally report less pain; they function better and are less likely to suffer with depression than unpartnered patients. Studies show that chronic pain patients experience lower levels of pain on days that begin with a sense of being happily connected to their partners; thus, relationship

status can affect the patient's experience of pain on a day to day basis. However, the research suggests that the pain-related advantages of being partnered only accrue to those who are in satisfying relationships, and even then, not in every case. When relationships are weak and distressed, pain patients tend to do poorly. They report more frequent and intense pain and show higher levels of disability. This may seem obvious on the surface, but the more you think about it, the more interesting it becomes. These researchers controlled for diagnosis. That means that patients with the same diagnosis, who had the same level of pathophysiology, experienced physical distress as a function of their relationship status, not their physical disorder. That is profoundly important and the underlying causes are not at all simple or obvious.

## Catastrophic Thinking: When Chronic Pain Goes Off the Deep End

We can define catastrophic thinking as the tendency to overestimate the likelihood of negative events occurring. To put it differently, catastrophic thinking involves worrying about all possible negative outcomes as if all were equally likely to occur. Thus, the logic that underlies catastrophic thinking is inherently distorted. Catastrophic thinking is common in chronic pain patients, regardless of the disorder that causes the pain. However, catastrophic thinking is especially problematic in facial pain patients.

Facial pain, and trigeminal neuralgia in particular, create a nightmare scenario for catastrophic thinking. The trigeminal neuralgia patient most often has a favorable response to neuroleptic medication upon first diagnosis, but this favorable response does not typically last. With time doses must be increased to achieve pain relief, and eventually, the patient reaches the maximum dose allowed. When patients reach the maximum dosage of neuroleptic, physicians typically turn to surgery. Surgery is often helpful, but with time, repeat surgeries are usually necessary to maintain pain relief. In most cases, there is a limit to the number of surgeries that can be successfully and safely employed. Patients know this. Thus, in very real ways, experience teaches the patient that the other shoe always

drops. This scenario creates a cognitive and emotional outlook that involves catastrophic expectations for many patients.

Still, the psychological challenges of trigeminal neuralgia (and other facial neuropathies) do not affect all patients in the same way. Some patients are relatively resilient and rarely become overwhelmed with catastrophic thinking. Other patients struggle with catastrophic thinking that is difficult or impossible to control. Why is this? Both anxiety and depression are associated with catastrophic thinking. Patients who struggle most with catastrophic thinking often have undiagnosed and/or untreated anxiety or depression. These patients frequently resist the idea that they could be depressed or anxious out of fear that a psychiatric diagnosis would lead others to view their pain as imaginary or relatively insignificant.

Patients who have a predisposition toward anxiety or depression often become depressed or anxious in the process of dealing with chronic facial pain. When this happens, it is not something that the patient could have

easily avoided. The challenge of dealing with intense chronic pain that has an unpredictable waxing and waning course can activate the underlying genetic predisposition to anxiety or depression in predisposed individuals. This heightened risk for depression and anxiety is present both for the patient and for their partner, who is also confronted by the demands of chronic pain, albeit from the perspective of a supportive loved one. When depression or anxiety goes untreated, catastrophic thinking will be robust yet difficult to recognize. Individuals understandably resist recognizing their catastrophic thinking as irrational or destructive because they fear that if they are not hypervigilant to potential catastrophe, they will be caught unprepared and unprotected. This hypervigilant approach might make sense if it were not for the fact that maintaining hypervigilance requires enormous energy. Considering that some feared outcomes are highly unlikely to occur, others are not as threatening as imagined, and still others cannot be avoided with any amount of preparation, expending the energy required to sustain a hypervigilant outlook is inefficiently taxing.



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Partners who are confronted with their loved one's catastrophic thinking understandably feel compelled to soothe their loved one, but their efforts inevitably fail over the long run. This is because catastrophic thinking is symptomatic of a cognitive disorder that is not amenable to change by reason. Neither will nurturance and understanding alone relieve the depression or anxiety that underlie catastrophic thinking. Psychotherapy is typically useful in identifying and eliminating catastrophic thoughts. Medications are often necessary to treat anxiety and depression in order to support this psychotherapeutic work.

When partners of chronic pain patients respond to catastrophic thinking with an effort to soothe the patient,

without also challenging the patient's catastrophic thinking and resistance to treatment, we refer to this as solicitous behavior. Although it is somewhat counterintuitive, it is not helpful to patients when their partners treat them solicitously.

## When Caring Hurts

Happily partnered pain patients with solicitous partners report greater pain severity than happily partnered patients with non-solicitous partners. Conversely, when relationship satisfaction is low, the association between the patient's reported pain and the solicitousness of their partner disappears. In other words, when the pain patient is in an unhappy relationship, there is no connection between the solicitous attention of their partner and the degree of their physical discomfort. Why this occurs is discussed later in this article. For now, the most important thing to understand is that being flawlessly attentive to a partner with pain is actually unhelpful and will likely result in the partner experiencing greater physical discomfort. The reasons for this are important to understand.

Optimal functioning in the context of chronic pain depends to a very great degree on the sense of oneself as capable and influential in one's own life. We refer to this competency as having a sense of personal agency. Dependency on one's significant other is destructive to self-esteem because it reduces the patient's sense of personal agency. The more global the dependency, the more the dependency threatens the patient's sense of personal agency. This is true even when the dependency is unavoidable, as it is in cases of advanced Parkinson's disease and multiple sclerosis. Dependency is not tantamount to closeness or loving. In fact, when partners must provide round the clock custodial care for extended periods of time, the dependency this creates can reduce the relationship to a patient-caretaker connection that is characterized by limited emotional intimacy. Interpersonal remoteness is not an inevitable outcome of relationships that involve extensive custodial demands, but it is a common one. Mental health professional support is beneficial to avoid this outcome.

***“Partner Relationships”...continued from page 11***

In cases of trigeminal neuralgia, patients are often globally dependent upon their partners following surgery. It is important for patients to move away from this extensive dependency as soon as possible to protect their self-esteem and the primary relationship. Doing so typically involves confronting significant fear of re-injury and functional limitation on the part of both the patient and their partner. While the move toward independence needs to be as expeditious as possible, it is understandable for the patient who is experiencing severe pain and discomfort to hope that their partner will regard their suffering as significant and respond with genuine compassion. Thus, one is justified in asking when and why caring for one's partner becomes destructive and how to avoid this outcome.

Solicitous individuals are consciously motivated to ease the discomfort of their partners who suffer with chronic pain. The solicitous partner is also unconsciously motivated to ease their own discomfort in response to their partner's suffering. The reflexive and consistent attention solicitous individuals pay to their partner typically involves an effort to aid their partner in identifying and avoiding situations that provoke pain. This effort has unintended negative effects. Nonetheless, the partner's solicitous helping behavior is communicative in the sense that it demonstrates compassionate concern, and, as a result, the solicitousness is often welcomed. This creates a dynamic where solicitous behavior is more likely to occur. The problem with this dynamic is that it fosters catastrophic thinking in both the patient and their partner.

The devolution into catastrophic thinking is far more likely to occur when either partner suffers with depression or anxiety, whether diagnosed or not. With long lasting episodically intense chronic pain, many individuals who would not otherwise have developed depression or anxiety begin to emotionally struggle and their thinking becomes catastrophic. Over time, as both partners focus progressively more on avoiding potential triggers for pain, their shared hypervigilance becomes an organizing principle of the relationship. The couple's shared hypervigilance is intended to avoid catastrophic outcome. Because catastrophic thinking is associated with greater pain intensity and increased disability, the patient functions less and less well as time passes. Their partner becomes more solicitous in an attempt to halt the patient's decline. The result is a downward spiral toward

***“Partner Relationships”...continued on page 13***



**Ramesh Babu MD,**  
Associate Professor of Clinical Neurosurgery



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disability on the part of the patient and exhaustion on the part of their partner. The most relationally lethal aspect of this dynamic is that the two partners become merged in a way that destroys the uniqueness of each person. This happens because both individuals give up activities that they find meaningful and enjoyable in deference to fighting the battle against pain. The very qualities that drew these individuals to one another are diminished as their roles devolve into the rigidly defined functions of patient and caretaker.

Trigeminal neuralgia presents great challenges to relationships because of its associated pain intensity and typically episodic nature. Trigeminal neuralgic pain is vicious. When it strikes, the patient is inevitably consumed by it and it is obvious to anyone in proximity to the patient that something awful has transpired. When significant others witness these attacks they feel understandably frightened and inadequate. What loving partner would not want to avoid this experience both for themselves and their significant other? The painful attacks of classic trigeminal neuralgia are typically followed by a pain-free period, the duration of which is unpredictable. This creates a psychological context wherein both members of the relationship are vigilant to the return of pain and are motivated to do whatever possible to avoid its return. As this dynamic expands over time, the pain-free periods become contaminated with hypervigilance and fear. The relationship is made unrewarding and toxic as both partners lose their capacity for connection outside of the context of fear. Both partners' energies are consumed by hypervigilance as they watch and wait for the next attack of facial pain. Despite every effort, the pain of trigeminal neuralgia typically does return. Thus, it is not hard to imagine how this could lead both individuals to become entirely focused on avoiding pain triggers, some of which are unknowable, and some of which are inconsistent in their triggering effects. It is in this way that chronic facial pain can take over a healthy relationship, distort it, and devitalize it.

When relationships are unsatisfying and conflicted, the risks of devitalization in response to chronic pain are proportionally greater than for persons in healthy relationships. In dysfunctional relationships, the partner's solicitous behavior is contaminated with anger and

resentment from the start. Because the patient has historically doubted their partner's commitment to the relationship, the partner's response to the patient's pain behavior is viewed as an indicator of the relationship's status. The context of pain gives rise to a series of interpersonal tests. In this way solicitous behavior is more than an effort to ease suffering. From the start solicitous behavior is rife with meaning that is wholly unrelated to pain.

## Pain Behavior as a Plea or a Punishment

Most psychologists keenly focus on childhood history as an important predictor of adult behavior. This is because we develop our core sense-of-self, our identity, during childhood. We learn to trust during childhood. We learn to perceive the world as fundamentally safe or threatening during our earliest years. We learn to see ourselves as capable or inadequate. If we are treated empathically by those who care for us, we learn to feel empathy for others. If we are loved, we learn to love. We learn all these traits in the course of our relationship to primary caregivers during our developmental years. If we experience significant abuse or neglect at the hands of our primary caregivers during these developmental years, we learn that emotional closeness brings pain. We learn that it is dangerous to trust. We learn that people are self-serving and must be manipulated in order to secure our interpersonal needs. All of this learning occurs as a function of early experience. These lessons are not conscious; they are not chosen by the child; they are not the responsibility of the child. Hurtful early experiences leave their mark in the structure of identity like so many cuts. As we grow, we learn ways to cover these cuts, to compensate for them, and these lessons shape our personality. If we feel threatened, we learn to protect ourselves with arrogance. If we fear abandonment (an almost universal fear among persons who have experienced early emotional trauma) we learn emotional ways of capturing the people we most cherish. We become possessive and controlling. The effects of childhood trauma are exceedingly complex and highly distinctive from person to person. Many factors are at play in the development of identity, and the result is

tremendous diversity person to person. Nonetheless, those who have endured childhood neglect or trauma typically struggle to form satisfying relationships as adults.

When individuals with histories of early trauma develop chronic pain, their medical course is inevitably complicated by psychological overlay. Their relationships are powerfully affected as well and this in turn further complicates medical course. When both partners suffered early abuse, as is often the case, the challenges associated with either partner experiencing chronic pain are enormous.

As previously explained, persons with histories of childhood trauma most often fear abandonment. This is understandable. The individual’s childhood relational experiences taught them that people upon whom you depend will hurt you. You cannot trust that others will be consistent in their attachment. When you are not useful,

of trigeminal neuralgia strikes. In the moment of painful suffering patients can offer very little, perhaps nothing, to “earn” the love and affection of their partner. Thus, it feels as if the pain has rendered them useless. This is a terrifying experience for an individual who lives in more or less constant fear of not being good enough to secure the affection of their partner.

When partners respond to their loved one’s suffering with nurturance, this eases the patient’s terror of being abandoned. This has nothing to do with pain; it is purely psychological. But it is attached to the experience of pain by context. The attentive partner not only meets the patient’s need to be nurtured in the moment of experiencing pain, they meet the patient’s unconscious longing for succorance that is residual from a traumatic childhood where the need to be loved and protected went unmet. This dynamic creates deep confusion because the experience of pain, and the need to be cared for are confounded. Adding to this complexity is the fact that individuals are never fully conscious of these psychological dynamics. They are only aware that the experience of being comforted in the context of pain eases their suffering. All of this psychological complexity is simply attributed to the experience of easing physical pain. And, over time, both the patient and the partner confuse emotional suffering with physiological pain. This can substantially complicate treatment. The confounding of emotional suffering and pain often leads to use of unnecessary medications and unnecessary invasive intervention that do nothing to ease suffering because these treatments are directed at the wrong cause for suffering.

Once the experience of pain is blended with the emotional longing for nurturance, relationships inevitably suffer. Pain behavior becomes intensely communicative but indirect and inaccurately representative of underlying emotion. The patient expresses their longing to be loved and held in esteem through their pain behavior. The partner may respond solicitously in an effort to ease long standing relational conflict or their own fears about abandonment. The unfortunate effect of this is that pain behavior usurps the couple’s communication process.



when your needs conflict with those of your loved one, you are dispensable. Imagine the despair such a person might feel in relationship to another when the intense pain



Appeals for nurturance and obligatory solicitousness are wrapped up in the language of pain behavior and thereby obscured from awareness. Real interpersonal problems go unaddressed. With time, both partners begin to feel exhausted and resentful. The patient may sense a growing distance from their partner. This can generate a panicky fear of abandonment, which exhausts the body and lowers resistance to pain. As panic builds, pain and emotional suffering increase; along with this intensifying panic, pain behavior becomes more dramatic. The patient's pain behavior at once constitutes an unconscious plea to be comforted and a test of their partner's commitment and love. The partner begins to feel that nothing they do helps; but, they are captured by the expectation that they will go on trying. These dynamics typically lead to unacknowledged anger on the part of both partners. The self-fulfilling prophecy that no one really cares, or remains connected, is thusly brought to bear.

Frustration, fear, and anger build in both partners when relationships are overcome by a distorted focus on pain and the related failure to see deeper interpersonal problems. In the context of escalating negative emotion, the patient's pain behavior and the partner's response to it can take on punishing properties. Again, this dynamic typically operates at an unconscious level for both partners. By this point in the life of the relationship, pain behavior has become wholly detached from the physiology of pain, although neither partner typically sees this. Pain behavior has become principally communicative and is no longer an accurate indication of underlying, associated physical discomfort. But again, this is not something that either partner fully knows. Pain behavior functions as a means to control the partner, and at times, pain behavior functions to punish the partner for perceived slights. Refusal to join the partner in shared activities because of pain, refusal to accompany the partner on visits to extended family because of pain, refusal to share time with children because of pain - these behaviors and others can function as punishment for perceived slights. The partner's refusal to spend time with the patient, refusal to engage the patient in recreational activity, care-taking that is obligatorily robotic, heightened criticism about the patient's limitations - these behaviors and others can also be punishing. These dynamics are complicated by the fact that the patient likely has some genuine experience

of pain, but appropriate support during these episodes is not forthcoming. The authentic connection that would generate a caring response has been destroyed by the erosive effects of pain behavior that has taken on a life of its own in a dysfunctional relationship. There is no solution for these problems apart from awareness. Once mired in relational conflict, professional help in the form of psychotherapy is typically required to overcome the muddled communication that dominates the relationship.

#### Tips for Managing Chronic Pain in Primary Relationships

1. If you have a history of childhood abuse or neglect, and you haven't talked this out in therapy, you need to do this. It is not necessary for the therapy to focus on your experience of pain in order to help your pain.
2. If you suspect that you have depression or anxiety, it is essential to get treatment. Successful treatment may necessitate use of a medication. While primary care physicians can successfully treat mild depression or anxiety, moderate or severe symptoms should be evaluated and treated by psychiatry. Again, it is not necessary for this kind of treatment to focus on your pain in order to help your pain. Mild depression and anxiety can be successfully treated without medication through participation in cognitive behavioral therapy.
3. Catastrophic thinking related to the experience of pain needs to be treated in psychotherapy. Treatment is optimal when the psychotherapist has experience in pain management.
4. Keep in mind that catastrophic thinking can develop in the partner as well as the pain patient. When this occurs, it is just as important for the partner to seek treatment as it is when catastrophic thinking develops in the pain patient.
5. Remember that it is hard to see catastrophic thinking as distorted when you are in the middle of it. If your partner suggests that you are worrying too much, try not to see this as unsympathetic. Your partner may be right. The only way to know for sure is to engage in the work of psychotherapy. This work may not need to last longer than a few sessions.

*"Partner Relationships" . . .continued on page 16*



6. Awareness is key to managing chronic pain. Even in the best of circumstances, where relationship satisfaction is high, lack of emotional awareness can create a context where pain behavior usurps the communication process and threatens the relationship. This inevitably leads to a cycle of increasing pain and disability. While it is very difficult to do, it is essential to differentiate the emotions of fear, disappointment, and anger within the relationship from those emotions that arise in response to pain. This will keep pain from taking over a central position in the relationship.

7. It is natural to feel comforted when your partner obviously understands that you are in pain. The experience of pain can be emotionally isolating. No one can feel your pain as you do and this can lead to loneliness. Even in the context of a healthy primary relationship the unshareable nature of pain is deflating. Thus, when your partner sees and acknowledges your physical suffering this can feel connecting and emotionally relieving. Nonetheless, it is critically important that you continue to seek connection in ways that have nothing to do with pain.

8. The crushing loneliness of pain is an important issue in its own right, and it is often helpful to talk about it. These discussions are most helpful in the context of psychotherapy with a pain management specialist. The therapist has discussed the experience of chronic pain

with many people. She or he has developed a specialized understanding of the difficult emotions that are universal among chronic pain patients. You do not have to take care of the therapist. There is no expectation of reciprocity. This eliminates the guilt that can accompany frequent discussions of pain-related negative emotions with your partner while at the same time easing the loneliness of chronic pain.

9. Mind-reading is error prone. Do not expect your partner to know what you need or feel without verbally expressing your emotions. Work to identify what it is that you are feeling then express these emotions in words.

10. Do not let conversations become dominated by discussions of your pain. In every primary relationship there is a shared emotional life that is both complex and impossible to fully understand without honest conversation. Pain-related experience is but one part of this emotional life. If conversations frequently focus on your pain to the exclusion of other topics, the relationship will be starved of the resources needed to keep it alive.

11. Do not allow your partner to do for you what you are capable of doing for yourself. Do not do for your partner what you know they can do for themselves as a means to communicate your concern. Communicate your concern with words. Commit to having a loving honest



conversation about the problem at hand to determine what is reasonable to expect of one another, especially when the limits of the patient's ability are not clear. The point is to shield the patient against the loss of personal agency and to protect the partner from falling into the exclusive role of primary caregiver.

12. When you are experiencing pain, it is your responsibility to do what is necessary to secure comfort. This may take the form of verbally asking for help. When asking for help, be as specific as possible about what it is you need. Being responsible in the context of chronic pain may take the form of limiting your activity without expecting your partner to similarly limit their activity. It will certainly entail doing things that you are generally frightened to do as much as it will entail avoiding things that you know will cause you discomfort.

13 Do not confuse care-taking with love. While these things are often related, they are not the same.

14. A loving partner will attempt to remain connected as you experience the intense pain of trigeminal neuralgia. Understand that this experience is as terrifying for them as it is for you. Their experience of helplessness can be as great as yours. As soon as you are able to authentically move away from focus upon your pain, do so. This will be reassuring for you and your partner.

15. Lastly, remain as functional as you possibly can. Work to retain activities that bring you pleasure and infuse your life with meaning. Chronic pain can be psychologically cancerous. The psychological effects of chronic pain can overtake your life and reduce you to being nothing more than a pain patient. The threat of this occurring is universal among chronic pain patients. Losing yourself to pain is not a product of emotional weakness or egocentricity. You must work to prevent this process from unfolding, and this work very often requires professional support. Reaching out for professional help is not a sign of failure. It is a sign of personal power. ●

# The Gender Gap in Pain

By LAURIE EDWARDS

The New York Times

To the list of differences between men and women, we can add one more: the drug-dose gender gap. Doctors and researchers increasingly understand that there can be striking variations in the way men and women respond to drugs, many of which are tested almost exclusively on males. Early this year, for instance, the Food and Drug Administration announced that it was cutting in half the prescribed dose of Ambien for women, who remained drowsy for longer than men after taking the drug.

Women have hormonal cycles, smaller organs, higher body fat composition — all of which are thought to play a role in how drugs affect our bodies. We also have basic differences in gene expression, which can make differences in the way we metabolize

drugs. For example, men metabolize caffeine more quickly, while women metabolize certain antibiotics and anxiety medications more quickly. In some cases, drugs work less effectively depending on sex; women are less responsive to anesthesia and ibuprofen for instance. In other cases, women are at more risk for adverse — even lethal — side effects.

These differences are particularly important for the millions of women living with chronic pain. An estimated 25 percent of Americans experience chronic pain, and a disproportionate number of them are women. A review published in the *Journal of Pain* in 2009 found that women faced a substantially greater risk of developing pain conditions. They are twice as likely to have multiple sclerosis, two to three times more

likely to develop rheumatoid arthritis and four times more likely to have chronic fatigue syndrome than men. As a whole, autoimmune diseases, which often include debilitating pain, strike women three times more frequently than men.

While hormonal, genetic and even environmental factors might influence the manifestation and progression of autoimmune diseases, we don't yet know the reason for this high prevalence in women.

Pain conditions are a particularly good example of the interplay between sex (our biological and chromosomal differences) and gender (the cultural roles and expectations attributed to a person). In 2011, the Institute of Medicine published a report on the public health impact of chronic pain,



called “Relieving Pain in America.” It found that not only did women appear to suffer more from pain, but that women’s reports of pain were more likely to be dismissed.

This is a serious problem, because pain is subjective and self-reported, and diagnosis and treatment depend on the assumption that the person reporting symptoms is beyond doubt.

The oft-cited study “The Girl Who Cried Pain: A Bias Against Women in the Treatment of Pain” found that women were less likely to receive aggressive treatment when diagnosed, and were more likely to have their pain characterized as “emotional,” “psychogenic” and therefore “not real.”

Instead of appropriate care for physical pain, this can lead to treatment for mental health issues

that might not even exist. The situation is further complicated by the fact that antidepressants are absorbed differently in women and vary in effectiveness, depending on hormonal cycles.

The routine attribution of abdominal pain from conditions like appendicitis or gastrointestinal disease to gynecological problems can also delay or complicate the diagnostic process. A 2008 study published in the journal *Academic Emergency Medicine*, designed to gauge gender disparities among emergency room patients complaining of abdominal pain, found that even after adjusting for race, class and triage assessment, women were still 13 to 25 percent less likely than men to receive high-strength “opioid” pain medication. Those who did get opioid pain relievers waited an average of 16 minutes longer to receive them.

Conditions like fibromyalgia or chronic fatigue syndrome, for which definitive causes have not been identified and concrete diagnostic tests are not available, illustrate the problems associated with the perceived reliability of the female patient as narrator of her pain. Women are more likely to receive diagnoses of many of these more nebulous conditions — fibromyalgia, which affects about six million patients in the United States, is nine times more likely to be diagnosed in women than in men — and this discrepancy surely contributes to the widespread skepticism that still exists over the legitimacy of these disorders.

I AM a sufferer of pain and chronic disease. Like many, I’ve had physical symptoms (in my case, respiratory problems and infections) explained away as emotional. My freshman year in college, I was in the emergency

*“Biology” continued on page 20*



room, flanked by machines and struggling to breathe while doctors lobbed questions at me: Why wasn't I responding to the medication the way they expected I would? Was I just too anxious? Could I not handle stress, and was that making me sick?

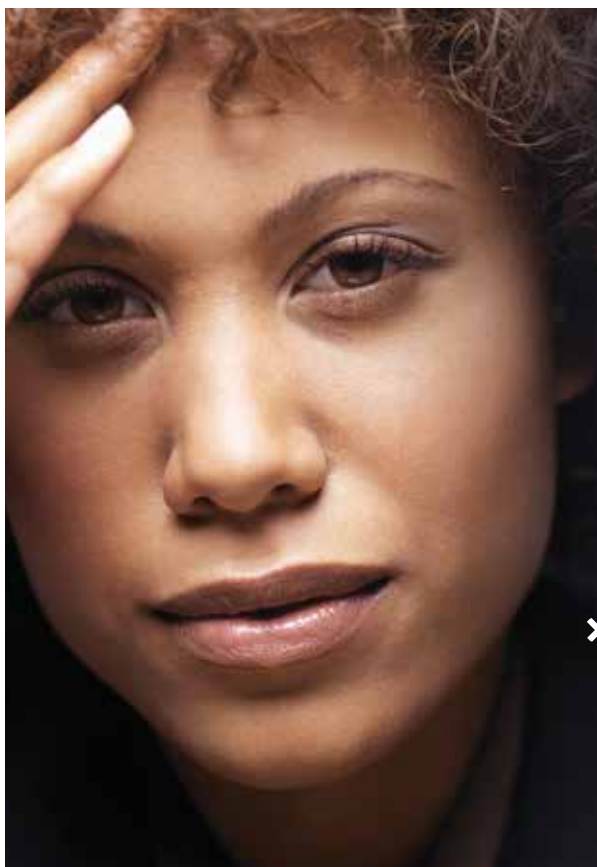
I was 23 before I was given a correct diagnosis of a rare genetic lung disease called primary ciliary dyskinesia. I'd been sick since birth, but long diagnostic journeys are occupational hazards of living with conditions doctors don't often see. Still, my journey was unnecessarily protracted by my doctors' dismissal of my symptoms as those of a neurotic young woman.

For all the medical advances of the past few decades, we still know shockingly little about pain and how to control it. Sex-based research is a crucial part of understanding not just the underlying mechanisms of pain, but the most effective ways to treat it for men and women alike. The Institute of Medicine report found gaps in research, particularly in terms of effective treatments, as well as in the oversight of pain research.

Among those improvements must be a renewed focus on discovering why women respond differently to some drugs and diseases, as well as an emphasis on training physicians to better diagnose and manage women's pain. A report by the Campaign to End Chronic Pain in Women found that inadequate physician training in diagnosing and treating just six pain disorders that affect women either exclusively or predominantly, including fibromyalgia and chronic fatigue syndrome, added as much as \$80 billion a year to America's health care bills.

Part of the reason the diagnosis and treatment of women's pain lag so much is simply the pace of medical research itself, which is slow to move from publication to clinical practice. Unfortunately, if anything, changes in assumptions about gender evolve even more slowly. ●


Laurie Edwards is the author of the book "In the Kingdom of the Sick: A Social History of Chronic Illness in America" and a writing teacher at Northeastern University.



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## WHAT YOUR DOCTOR NEEDS TO KNOW

by Carol James

### About the Author:

Carol James recently retired as Physician Assistant with The Johns Hopkins Hospital Department of Neurosurgery where she provided continuity of care for TN patients and their families.

As a patient, your life was going along as usual until one day, out of nowhere, you feel an awful, electrical facial pain, and life is never the same. Most of you will head for the dentist, as the only thing you can imagine this to be might be a dental problem. The dentist may do x-rays, examine you, and possibly even do a procedure or two. Usually this does not stop the problem, or it could even make it worse!! If you are fortunate, the dentist will suggest that this may be neurological, and you are seen by your primary care physician or a neurologist. You think you will die and this is what you want to tell your doctor, but it doesn't help him to know what you are feeling or what he can do about it. You need the tools to tell this person the details about this pain so that together you can discover the diagnosis and make a treatment plan.

Your doctor may have requested records and scans be sent ahead. Please do as requested. However, don't arrive in your doctor's office with a 6" stack of records, as it is impossible

for him to review all of this material in the context of a consultation, and this will lead to frustration by all concerned. Instead, have your information organized (with an extra copy for the doctor). You need to have a good description of the pain. What does it feel like (shocking, stabbing, hot, cold, numb, lightning bolt, electric cattle prod, zapping...)? Exactly where does the pain begin and where does it spread? Can you make a map of the pain?

Your doctor will also ask what brings the pain on or what makes it worse (talking, eating, opening your mouth, flicking your tongue around your mouth, touching your face, shaving, applying makeup, tooth brushing, bending over, sleeping on that side, putting the phone to your ear, wind or cold or air conditioning on your face, riding in a car, walking)? How long will an individual pain last or the entire pain session (I know it feels like forever, but how long does it actually last)? Some patients will say that it is always there, but is it? Or is there a hypersensitivity all of the time and every little thing you do may bring it on. This is analogous

*"Doctor Needs to Know" . . .continued on page 22*





to the difference between a straight line (constant pain) and a jagged, spiked line (intermittent spikes of pain).

How long have you suffered with this pain? Try to remember when you very first had facial pain. You may have had it intermittently with short or long periods of remission where it went away completely or got much less sensitive. Remember those times when your friends or family questioned you because last week you couldn't talk or go out to eat, and this week you can do those things??? Give a sense of how the pain may come and go.

Be able to inform your doctor which medications you have tried for this condition? What effect did each one have (regardless of the side effects which may have made you discontinue them - did they help your pain before you stopped them)? How long did you try each one and what was the highest dose you used? This is important to determine if you tried a sufficient dose, as it may take higher doses to control more pain.

Have you had any procedures for this pain? If so, know exactly what those procedures were and have copies

of the surgical reports. These can include blocks, dental procedures, sinus surgeries, plastic surgeries, radiosurgery (gamma knife/cyberknife), rhizotomies, microvascular decompressions, stimulators, etc. The more detail you can provide about these procedures, the more information the neurologist or neurosurgeon has to recommend a procedure and predict its success.

Have you had a CT or MRI scan of the brain? Fine cut MRI with magnified views of the cerebellopontine angle (where the trigeminal nerve is located) with and without Gadolinium (contrast) is the gold standard for seeing any vascular compression or other pathology on a scan. This scan on CD needs to be provided to your neurologist/ neurosurgeon, not just a report. The anatomy will need to be reviewed. Surgeons, in particular, need to see that anatomy if they are contemplating surgery.

Please provide your past medical history. List all major illnesses, hospitalizations, and surgeries with dates. Have you had any problems with anesthesia - if so, list them. List all current medications (both prescription and over the



counter drugs) and their dosages. Don't forget the aspirin, garlic, Vitamin E, fish oil or Ibuprofen - they can all have an effect on bleeding and clotting and must be stopped at least 7-10 days prior to surgery. For your safety, do not withhold this information. If you have allergies, remember what the drugs are that have made you sick, and exactly what the drug did to you. If you don't remember, contact your primary care physician to see if they have this list. Have you had a history of herpes (fever blisters, cold sores, shingles, chickenpox)? Do you have any family history of major illnesses - list them. Since you have just gone to all the trouble of putting this together, please make sure that you keep a copy for yourself, as it will be helpful in the future for other physicians, and you don't want to compile it again!!

I know it seems like a lot of trouble to put all of this together before your appointment. But remember, it is nerve-wracking to see a new practitioner. You will tend to forget the details - and most of you are on medications which can alter your memory - so it is perfectly normal to forget details or wish you had said more. Be your own advocate and make sure you have the information already

summarized, so you can provide all of the information that is necessary.

Bring another person with you to the appointment - I would suggest that this be a spouse, significant other, or a good friend. You definitely need another set of ears to help you remember what has been said. That person can take notes while you pay attention to the conversation. Ask if you can tape the meeting, so that you can review the information later. Ask for handouts or a website to review or to share with others who want to know what was said - your memory is not the best recollection of the meeting. Get a business card so that you can communicate with this physician and determine the next step - a future appointment, phone call, e-mail or fax, but make sure that you understand the next step in the process and your expectations and those of your doctor.

Be proactive, and know that this requires teamwork. With a good understanding of the problem (yours and the physician's) and a plan, the pathway to treating your pain will have begun. ●



# COMING OUT OF THE FACIAL PAIN CLOSET



Being diagnosed with trigeminal neuralgia, or any chronic illness, is no easy pill to swallow. Receiving the diagnosis can be both scary but also oddly welcoming -- getting validation of your pain can be a relief. One challenge that comes along with trigeminal neuralgia is figuring out how to tell people in your life about this condition they most likely have never encountered. Various questions may come to mind: Do you tell them? How long should you wait? How much should you tell them? Will these people think differently of me?

While disclosing your health conditions is a personal choice, we on the YPC are coming out of the proverbial closet to share our stories about when and how we told different people about having trigeminal neuralgia.

## HOW WE TOLD OUR FRIENDS, FAMILY AND OTHERS ABOUT OUR TRIGEMINAL NEURALGIA

### COMING OUT TO MY FAMILY

I told my family members about TN after I finally had a true understanding of what was actually taking place inside my body. My family immediately rushed to look it up and found some situations that were better than mine but some that were worse. It's very difficult to hide

TN pain, especially when you have constant as opposed to episodic pain. I did my best to put a smile on my face and push through each day. Family members would often say that I "looked good," and, in a way, I liked hearing that because it meant I was hiding the pain well and seemed "normal." Words could never truly describe the pain to them, though. But they tried.

### COMING OUT TO MY FRIENDS

I recently made a new friend and we have become quite close. She and I quickly learned that we had a lot in common: we're moms to all boys, we both hate the color yellow and, strangely enough, we even have the same haircut. I briefly mentioned at that first playdate that I had a disorder that affected the nerves in my face. I knew from our first playdate that she "got" me, which became even more obvious after she became aware of my battle against trigeminal neuralgia. I tend to be somewhat private and reserved and therefore didn't go into much detail. My friend took it







upon herself to do her own research on TN and neuropathic facial pain. Before I knew it, she was offering to help me raise funds toward research! Sometimes it takes a perceptive person to hear the things you can't say and I am thankful to have such a person in my life!

## COMING OUT TO MY TEACHERS

I told my high school teachers about TN before I even met them. The minute I got my class schedule for the following school year, I emailed my new teachers and informed them of my situation. I never let them see me in pain, so they never truly understood what I was going through, but they were understanding of my situation nonetheless. This year, I started college and I have yet to tell any of my professors. I'm in remission due to a successful MVD, so it doesn't

seem like such a big and important part of my life. I'm excited to be the "normal" student again, so I'm not going to give them a reason to look at me differently unless I have to. But having gone through it already with my teachers in high school, I know that communicating and educating about my condition will help them understand if I ask for extensions on projects or other accommodations. I hope it doesn't come to that, but I'll be ready if it does.

## COMING OUT TO MY SPOUSE

I told my husband about TN before we started dating. In conversation, he had heard me talk about surgeries, medications and missing school. I was comfortable sharing little bits and pieces with him because, at that time, my pain was manageable, which made it easier for me to talk about. Ten months into our relationship,

my pain drastically increased. It was at that point I shared more with him about my pain, triggers and limitations. I was afraid he was going to be scared and not want to be with me, but the opposite happened. My pain added new challenges, but they helped us learn how to overcome obstacles we faced in our relationship. I learned how to communicate when I was having more pain and what he could do to help, and together we figured out that we needed to be flexible in our plans. TN requires a lot of give and take on both of our parts but in the end, I truly believe it made our relationship stronger.

## COMING OUT TO MY EMPLOYEES

I tell my employees right away about TN and I share TN information often. I feel that it is important for them to know what I deal with and why, for example, some staff meetings may

*"Coming Out"...* continued on page 26



be different than others because I still experience pain on a regular basis. I think it is important for staff and the team to know that there are days I may struggle; I want them to know that I will also support them in whatever personal issues they may be experiencing. More importantly, I want my staff to feel empowered and encouraged by the fact that I am willing to share my story and share my pain. We all face our own type of battles, and I want my team to know that if we share and take care of one another, we are stronger as a department.

## COMING OUT TO MY CO-WORKERS

The first people at work I told were the co-workers with whom I shared work duties. It wasn't something I really wanted to reveal, but transparency was needed in order to keep peace. I wasn't looking for sympathy or support but wanted them to be aware of my situation in the event I fell behind on my duties or had to miss a day of work. I always thought I hid the pain well, but as other co-workers saw the pain come and go, they made it easy to share my TN story by simply asking if I was ok or if there was anything they could do to help. I still have not told all of my co-workers that I have TN, but when an opportunity presents itself I use my story as a way to spread awareness.

## COMING OUT TO MY BOSS

I told my boss about my facial pain before I was even diagnosed with TN, since I needed a lot of time off of work for different appointments as I was trying to figure things out. Even though I was skeptical about letting my employer know so much of my personal business, I chose to be transparent so that I could ask for accommodations as necessary. As a result, my boss is extremely flexible about letting me work from home on high pain days. On the flip side, I have also had to up my game at work, so I am confident that she will never question my dedication and work ethic. The more I communicate with her about my struggles, the more flexible she is. As long as I get the job done, she does not care where or when I work.

## COMING OUT TO MY CHILD

I told my son about TN in age-appropriate stages. I had been battling facial pain for 13 years before he was born, but was not diagnosed until he was four. It was something I hid from many people in my life, but surgery forced me to be more candid about my condition. When I was scheduled for an MVD, I made my son a homemade social story book, explaining that mommy was going to have surgery on her head and what life would be like while I needed time to recover. I've since had four other surgeries and have explained much more to him, saying that mom's



face hurts and he needs to be gentle when it comes to things like jumping on me in the morning for kisses and hugs. He's learned the most by hearing me explain TN to other people and has picked up on how to pronounce trigeminal neuralgia quite well! It warms my heart whenever he corrects someone who says "tri-whaaaaat?"

There you have it. We have come out of the TN closet. Through our experiences, we have learned:

1. There is no right or wrong time to open up about TN. Everyone is different.
2. Give people a chance -- you don't know how they will react.
3. Knowledge is power. The more people know, the more likely they are willing to be flexible and understanding.

Will you regret opening up to people? Possibly, but we hope not. Will you have to answer more questions? Possibly, but awareness is spread one person at a time. Will people look at you and think, "wow, I never knew." Possibly. But in addition to educating your friends, family and co-workers, you also may help someone by sharing your story. We on the YPC have a mantra: "I don't want my pain and struggle to make me a victim. I want my battle to make me someone else's hero." The only way to achieve that is to tell your story. ●

For more information about the YPC [f](https://www.facebook.com/tnaypc)/tnaypc

## Young Patient Profile



**Name:** William Clark

**Current age:** 35

**Where do you live?** Willingboro, NJ

**How old were you when you first experienced facial pain?** Age 30

**How old were you when you were diagnosed?** Age 30

**What was your diagnosis?** My initial diagnosis was trigeminal neuralgia, type 2, on my right. Two months later, the pain started on my left, fast forward two years later and add on the diagnosis of occipital neuralgia, on the left.

**What do you do for fun?** When the pain allows, travel and go to the movies.

**What has TN taught you?** TN has taught me alot, but I have learned who will be in your corner and who won't be in your corner. Most of all, it has taught me that I was given this disease for a reason, to advocate and educate others.

**What treatments (non-surgical) have you tried?** Acupuncture and massage

**Have you had any procedures?** No

**How has your facial pain changed you?** Well, I go into what I call "hibernation" from November to March because of the cold weather. So this has taken a toll on my social life. I also have a two year old son. What I can do for and with him has changed because of my pain. It is definitely hard, for me to say "no, daddy can't do that."

**What tips do you have for other young patients?** Get a good support system around you, meet other TN patients- they are dealing with the same thing you are and can be a great addition you your support system, don't let TN stop you from doing what you want, and attend conferences, they are very informative.

## FPA Membership

The following individuals joined or renewed their FPA membership between September 1 and November 30, 2016

### SEPTEMBER

Mark Barthelme  
Deborah Elliott  
David Fulkerson  
David Julian  
Roger King  
Paul LaChance  
K. Stuart Lee  
Judy Licata  
Eric Lukens  
Jay Marks  
Tina Moynihan  
Laurie Rauch  
Cathy Ryan  
Mark Stenberg

Wolfgang Thomae  
Kim Westerholm  
Sara Bentley Wierda  
Kathleen Wiltse  
Carol Woodfin

### OCTOBER

Sarah Donly  
Thomas Dowdy  
Janet Fuqua  
Andrea Glenn  
Barbara Gonsalves  
John Hehnen  
Zach Huston  
Trevor Lissoos  
Jeffrey Norwood

Lynn Ruppe  
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## FPA's Memorial Tribute Fund

*There are special people in our lives we treasure. Increasingly, FPA supporters are making gifts in honor or in memory of such people. These thoughtful gifts are acknowledged with a special letter of thanks, are tax-deductible, and support FPA's growing initiatives on behalf of TN patients and families. We are delighted to share recent Memorial Tribute gifts received as of November 2016:*

### Honorary Tributes

**Melissa Anchan**  
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**Danielle Beard**  
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**EVERYONE'S** JOURNEY  
WITH FACIAL PAIN  
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The road to successfully treating trigeminal neuralgia can be a long one, especially if you've relied on medications for years with modest to little success. It's time to take a different road: outpatient, incisionless radiosurgery at The Valley Hospital's Gamma Knife Center in Paramus, New Jersey.

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Dr. Brisman is Chief of Neurosurgery at Winthrop-University Hospital and Co-Medical Director of the Long Island Gamma Knife® at South Nassau Communities Hospital.



Jeffrey A. Brown, M.D.

Dr. Brown is the chairman of the Medical Advisory Board of TNA-The Facial Pain Association. He is the Neurosurgery Director of the Winthrop-University Hospital CyberKnife® Program and Chief of Neurosurgery at Mercy Medical Center, Rockville Centre, New York.



Alan Mechanic, M.D.

Dr. Mechanic served as Chief of Neurosurgery at Huntington Hospital, in Huntington, NY, from 1996 to 2014. He is Chairman of the Nassau Surgical Society Section of Neurosurgery.



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