



## How to Find the Right Doctors to Effectively Treat Your Neuropathic Facial Pain

There are three steps to finding the right doctors:

1. **Understand the big picture:** It's important to understand the process and implications of getting good healthcare for a rare condition.
2. **Find a doctor:** It is more difficult to find the right doctors to treat a rare condition. However, there are some excellent resources available.
3. **Qualify the doctor:** It's important to ask the right questions – they will help ensure that the physician you choose will be qualified to treat your specific condition.

### Understand the Big Picture

Neuropathic facial pain is a rare condition that is not well understood by many medical professionals. Therefore, it is not surprising that most physicians will not have a deep understanding of the full range of treatment options, whether by use of medications, surgery, or alternative therapy. Treatment may involve more than one specialty, and handoffs between physicians may not always be seamless. Consequently, it is important that patients are active participants in developing and understanding their own treatment plan in conjunction with the providers with whom they meet.

Patients are encouraged to speak with an experienced neurologist or neurosurgeon about their symptoms. These specialists use established medical guidelines (<https://ichd-3.org/13-painful-cranial-neuropathies-and-other-facial-pains/13-1-trigeminal-neuralgia/13-1-1-classical-trigeminal-neuralgia/>) to help determine the exact type of facial pain and to get to a definitive and accurate diagnosis. Because facial pain can be complex, diagnosis may require multiple visits, imaging tests such as an MRI, and trying certain medications to see how symptoms change.

See the *Path to Wellness* document developed by the Orange County Support Group with guidance from Dr. Mark Linskey: <https://content.facepain.org/wp-content/uploads/2026/04/Path-to-Wellness-OC-TNA.pdf>

Important information to consider before an appointment would be to create a pain diary that includes the following characteristics of your pain: when the pain first occurred, where it was on the face, how the pain felt (e.g., tingling, lancinating,

burning, aching, etc.), its severity, its duration, and medications taken and their impact, if any. While it is important to give your treatment plan enough time to work, it is equally important to be ready to get a second opinion if the current plan is not working. By educating yourself about the different treatment options available, you will become better prepared to ask questions about your physician's proposed treatment plan and determine whether you still have confidence in it or if it is time to make a change. Chapter 1.2 of FPA's book ***Facial Pain: A 21st Century Guide*** addresses this in more detail.

The gold standard for care of patients with neuropathic facial pain is an individual with significant knowledge and experience diagnosing and treating these patients. This may include a multi-disciplinary team consisting of some or all of the following: neurologist, neurosurgeon, radiologist, orofacial pain specialist, pharmacologist and/or mental health professional. Such multi-disciplinary teams have become common in Europe. While the US is moving toward that model, these collaborative teams may still be difficult to find. In the US, patients are most likely to find a multi-disciplinary approach to care in university hospital settings, particularly those with neurology and/or neurosurgical residency programs. Typically, neurosurgeons who specialize in treating neuropathic facial pain and are affiliated with community hospitals also have an informal network of specialists in the field to whom they can refer patients when surgery is not indicated.

If you are just starting out on your facial pain journey, or if your pain is responding well to your treatment plan, it may be more convenient to see a local physician. Your primary care physician is likely to recommend a neurologist first. This is an appropriate starting point, but you should bear in mind that most neurologists do not specialize in neuropathic facial pain and may not have a lot of experience in treating the condition or have a deep understanding of the treatment options available. Headache neurologists are most familiar with neuropathic facial pain, and headache group practices will typically have one or more doctors who specialize in facial pain. However, there is a shortage of neurologists with headache specialization, and it may prove difficult to get a timely appointment with such an individual or group. In this case, it is better to seek out a general practice neurologist who can start you on a treatment plan immediately rather than having to wait in pain for an appointment with a facial pain specialist.

In many cases, dentists are the first healthcare providers people see when seeking a diagnosis for facial pain. They may refer you to an orofacial pain specialist—a dental professional trained to evaluate and treat conditions affecting the face, head, and neck. These specialists manage a wide range of issues, including temporomandibular

joint (TMJ) disorders, headaches, nerve-related (neuropathic) pain, and sleep disorders. Unlike general dentists, orofacial pain specialists focus on non-dental sources of pain in these regions. Recognized as a dental specialty by the American Dental Association only since 2020, orofacial pain is a relatively new field. As with headache neurologists, these specialists are highly skilled in treating nerve pain in the face but can be difficult to find.

Try to avoid your local hospital Emergency Room unless absolutely necessary as ER doctors are unlikely to be well-versed in the condition and may not come up with a correct diagnosis without your guidance. If you do find yourself in need of emergency treatment, take with you the FPA's recommended ER treatment guide, which is given in Chapter 2.2 of *Facial Pain: A 21st Century Guide* and can be downloaded at <https://content.facepain.org/wp-content/uploads/2026/01/Emergency-Room-Medication.pdf>.

## **Find a Doctor**

A person with trigeminal neuralgia (TN) or other forms of neuropathic facial pain will need to have a healthcare team that is trained and experienced in treating this condition. TN and other forms of neuropathic facial pain are rare disorders, so it's very important to find physicians who are experienced in your specific condition. Neurologists, orofacial pain specialists, and neurosurgeons are likely to be the most knowledgeable about this condition.

To find a neurologist, orofacial pain specialist, or neurosurgeon in a specific geographic area, there are many good sources to utilize:

- Ask for Referrals From
  - Members of a local FPA Support Group
    - Contact FPA support group leaders here: <https://www.facepain.org/find-support/about-support-groups/>
    - Contact FPA peer mentors here: <https://www.facepain.org/connect-with-11-support/>
  - Your primary care physician
  - Friends, family or others in the area who've had similar health needs
- Search Medical-Specialty Directories
  - Orofacial Pain Specialist
    - American Board of Orofacial Pain: <https://www.abop.net/default.aspx>
      - Search tool: <https://www.abop.net/search/custom.asp?id=2158>
- Neurologist
  - National Headache Foundation: <https://headaches.org/>
    - Search tool: <https://headaches.org/resources/healthcare-provider-finder/>

- American Migraine Foundation: <https://americanmigrainefoundation.org/>
  - Search tool: <https://americanmigrainefoundation.org/find-a-doctor/>
- Migraine Meanderings: <https://headachedoctors.net/>
  - Search tool: <https://headachedoctors.net/doctors/>
- Use Trusted Medical Directories
  - Healthgrades ([healthgrades.com](https://www.healthgrades.com))
  - Zocdoc ([zocdoc.com](https://www.zocdoc.com))
  - Vitals ([vitals.com](https://www.vitals.com))
  - RateMDs ([ratemds.com](https://www.ratemds.com))
  - WebMD Physician Directory ([doctor.webmd.com](https://www.doctor.webmd.com))
  - MediFind ([medifind.com](https://www.medifind.com))
  - American Medical Association Doctor Finder ([Find-doctor.ama-assn.org](https://www.find-doctor.ama-assn.org))
  - American Board of Medical Specialties ([abms.org](https://www.abms.org))
  - Federation of State Medical Boards ([fsmb.org](https://www.fsmb.org))
- Search Hospital Affiliations
  - Doctors affiliated with well-regarded hospitals or medical centers often meet high standards. Ask for recommendations from your primary care physician and others knowledgeable about this topic.
  - Use Recognized Top Medical Center Ratings
    - U.S. News & World Report ([health.usnews.com](https://www.health.usnews.com))
    - Becker's Hospital Review ([beckershospitalreview.com](https://www.beckershospitalreview.com))
- ChatGPT
  - Ask ChatGPT or other Artificial Intelligence applications for information (e.g., "Who are the highest rated neurologists in Milwaukee, WI, who represent that they treat people with trigeminal neuralgia?")

## Qualify the Doctor

Neurologists and neurosurgeons treat patients with many conditions. Given that trigeminal neuralgia and most other neuropathic facial pain conditions are rare, it is important to check to make sure that the doctor has experience treating your condition. Therefore, some of the questions you might want to ask the physician you are considering can be found below.

### **Key Questions for a Neurologist**

- How many years have you been treating people with trigeminal neuralgia (TN)?
- How many TN patients have you had in the past 5 years, and how many do you currently have?
- What do you typically do if your first line of treatment doesn't work?

- In addition to prescribing medications, are you open to your patients considering surgical procedures and complementary and alternative medicines (CAM) (e.g., acupuncture, medical cannabis, meditation and mindfulness, upper cervical chiropractic care, and others)?
- Have you referred TN patients to neurosurgeons or CAM providers, and if so, what percentage of your TN patients have been referred to other healthcare providers?

### **Key Questions for a Neurosurgeon**

- How many years have you been treating people with trigeminal neuralgia (TN)?
- How many procedures do you perform in a year, and when was the last one?
- What percentage of your surgeries are microvascular decompression procedures (MVDs) as opposed to other neurosurgeries?
- What is your personal MVD success rate? What percentage are pain free at one year, two years, five years? (An inability to answer those questions may indicate a lack of follow-up. A less than stellar percentage indicates either poor technique or poor patient selection.)
- How do you define a successful MVD?
  - In most patients, a successful MVD is defined as complete pain-relief without the need for medications. In a minority of patients, the definition may not be as stringent for a variety of reasons.
- What is your personal complication rate?
- Do you treat both the medical and surgical aspects of TN? If not, is there someone you refer to?
- What do you do if you don't find any vascular compressions during surgery?
- If the surgery is not successful, what is your alternative treatment plan?
- What are the risks of the surgery?
- What procedure(s) do you do for TN other than MVD, and if you don't do one, is there someone in your group who does?

### **Keep in mind...**

- If the doctor does not answer these questions to your satisfaction, then you might want to consider a different physician.
- The neurologist and neurosurgeon should take a good history of your symptoms and ask enough questions to be able to come up with a differential diagnosis (e.g., possible causes), especially because some procedures, such as MVD, are only appropriate with a certain type of TN.
- The neurologist or neurosurgeon should have TN or MVD listed as a focus or subspecialty under their name. When searching, include those words to make sure that you find those with substantial experience, even within a multidisciplinary program.

- Read reviews! Look for reviews specific to TN and MVD, which may be more difficult to find, but could be very helpful in determining qualifications. Speak to other patients if they are willing to provide names.
- Experience matters! There is some evidence that a neurosurgeon who does 30+ MVDs per year achieves better outcomes than those who do fewer procedures. And there is evidence that hospitals that do 20+ MVD procedures per year have better outcomes than other hospitals.