



# OROFACIAL PAIN SURVEY

**pain**australia

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NOVEMBER 2021

## Respondent numbers

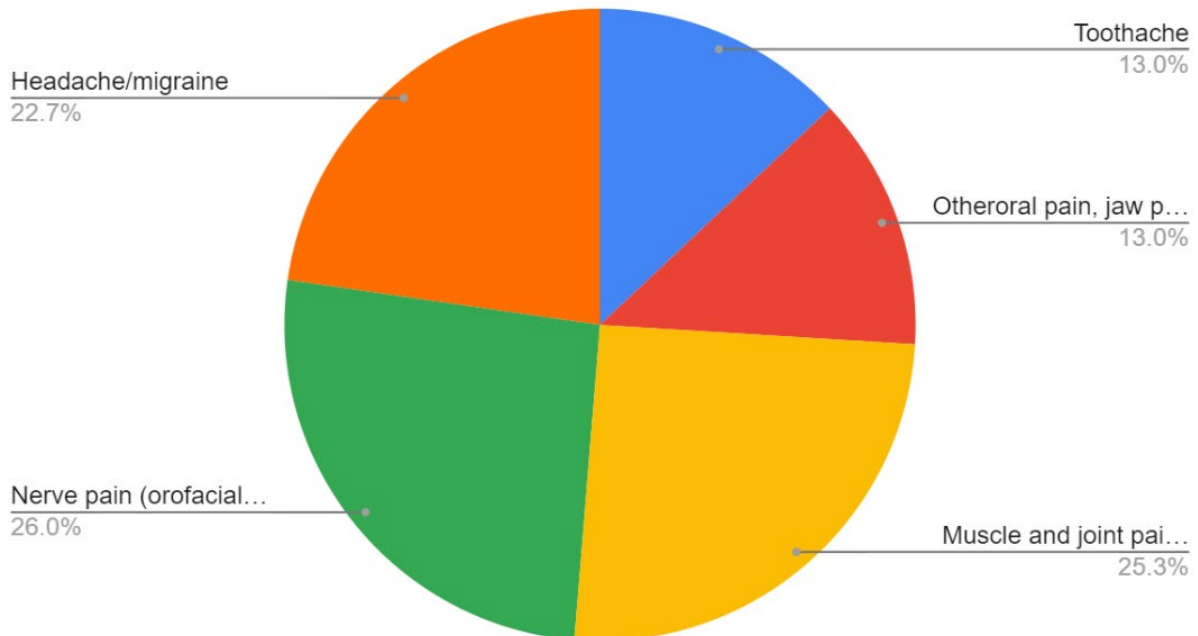
61 respondents consented to the use of their data.

## Do you live with any of the following types of orofacial pain? (Combined)

Many people reported having multiple conditions, hence there are more than 61 responses below. The % results are represented in the pie chart.

Type of pain	Reponses	%
Toothache	20	13%
Otheroral pain, jaw pain	20	13%
Muscle and joint pain (temporomandibular disorders)	39	25.3%
Nerve pain (orofacial neuropathic pain)	40	26%
Headache/migraine	35	22.7%

### Types of orofacial pain that respondents are living with

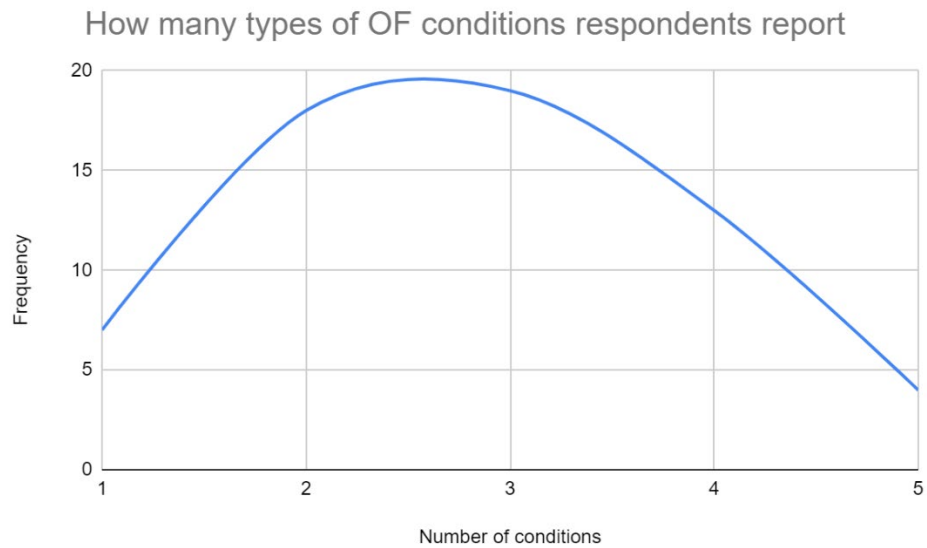


## Observations from more detailed data

- Majority of respondents reported multiple types of orofacial pain

Number of conditions	Frequency	%
1	7	11
2	18	30
3	19	31
4	13	21
5	4	7

- 31% of respondents were living with 3 types of orofacial pain, followed by 2 types (30%) and then 4 types (21%).
- Much less respondents reported 1 type (11%) and 5 types (7%)

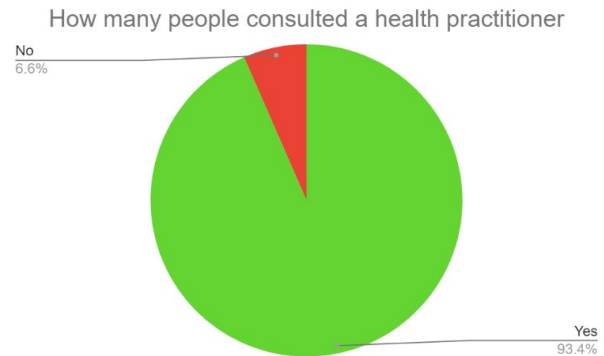


- Of the different types of orofacial pain, it was noted that nerve pain was experienced in isolation, where all other types were reported coocurrently.
  - 22% of respondents who reported nerve pain reported no other types of pain.

## Did you consult a health practitioner about this pain?

93.4% of respondents consulted a health practitioner about their pain.

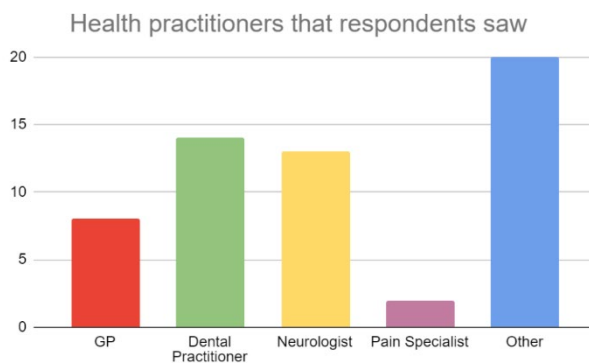
Yes	57
No	4



## Please specify who you saw:

Of these 14% saw a GP, 24.6% saw a dental practitioner, 22.8% saw a neurologist, 3.5% saw a pain specialist and 35.1% saw a different type of practitioner that was not listed.

Some of the practitioners that were listed as other included physiotherapists, rheumatologists, orthodontists, sleep specialists, the emergency department and ear, nose, and throat specialists.

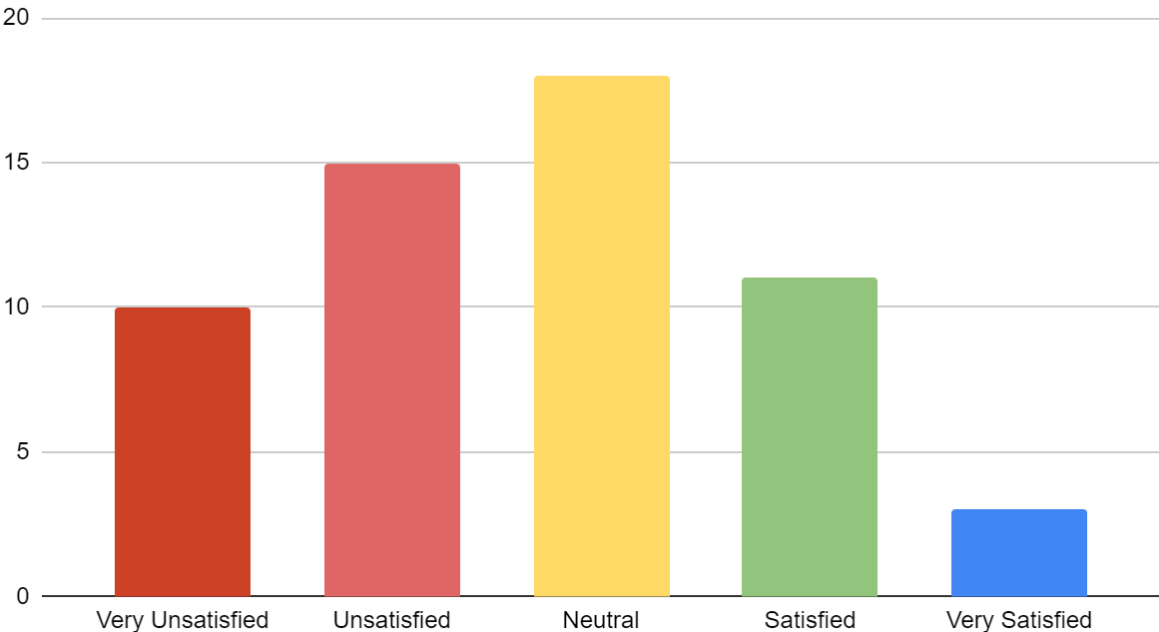


Practitioner	Respondents	%
GP	8	14.0
Dental Practitioner	14	24.6
Neurologist	13	22.8
Pain Specialist	2	3.5
Other	20	35.1
<b>Sum</b>	<b>57</b>	<b>100.0</b>

# Were you satisfied with the treatment options presented to you?

Rating	Answer	Percentage
Very Unsatisfied	10	17.5
Unsatisfied	15	26.3
Neutral	18	31.6
Satisfied	11	19.3
Very Satisfied	3	5.3
<b>Total</b>	<b>57</b>	<b>100.0</b>

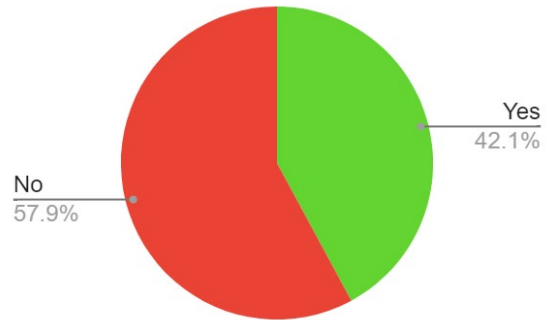
Reported satisfied with treatment options presented



## Did you feel that your medical practitioner was knowledgeable in how to treat this specific type of pain?

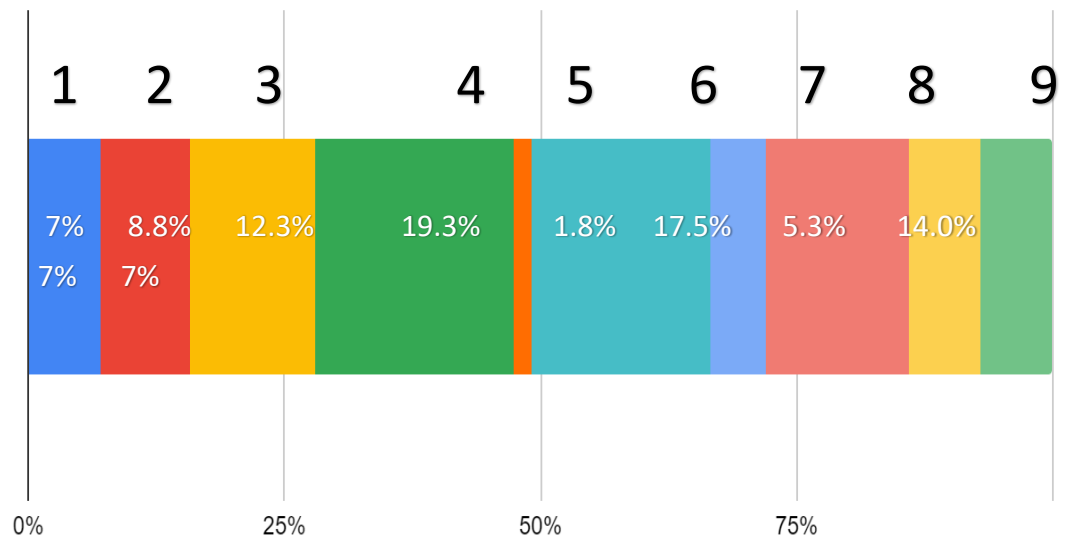
57.9% of respondents felt that their practitioner was NOT knowledgeable in how to treat their specific type of pain.

Yes	24
No	33



## How would you rate your medical practitioner's knowledge in how to treat this specific type of pain?

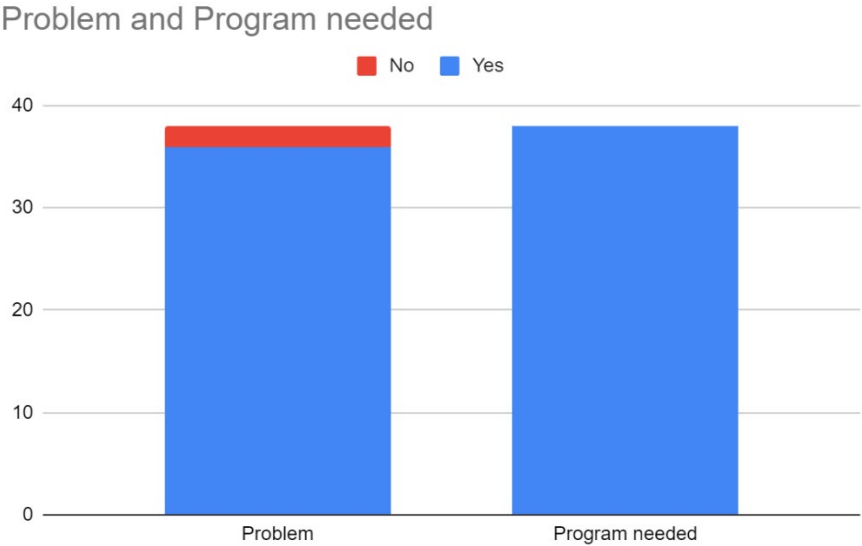
Scale	Rating	%
1	4	7.0
2	5	8.8
3	7	12.3
4	11	19.3
5	1	1.8
6	10	17.5
7	3	5.3
8	8	14.0
9	4	7.0
10	4	7.0



# Do you think that there is a significant problem in the Australian and New Zealand communities with the recognition and management of Orofacial Pain? Is there a need for a dedicated training program in multidisciplinary Orofacial Pain management?

93% of respondents identified that there was a significant problem in the Australian and New Zealand communities with the recognition and management of Orofacial Pain. 98% of respondents believed that a dedicated training program in multidisciplinary Orofacial Pain management was needed.

	Problem	Program needed
Yes	57 (93.4%)	60 (98.4%)
No	4 (6.5%)	1 (1.6%)



## Any other comments?

### Comments

I did my own research and found a GP on the Sunshine Coast who can offer me botox for migraines and TMJ (I have fibromyalgia) with under medical medicare so I only pay for the botox itself. Every 10-12 week \$350-400 still a lot but along with \$1800 specific TMJ hard large mouthguard (after about trying 6 others around \$500) my pain is around 75% less and tolerable. This information was not available on any of the sites I follow. It would have been very useful for the many years I have suffered from terrible TMJ. happy to talk more if required.

The knowledge of TMJ is OK but for Trigeminal neuralgia it's appalling depending where you live. I have been fortunate with GP, neurologist, neurosurgeon, and Oral & maxillofacial surgeon. My pain clinic experience was dreadful in my early days. I now have a superb pain Dr. As admin of NZ Trigeminal neuralgia support group I am appalled at lack of knowledge and the way many patients with Trigeminal neuralgia are treated in NZ.

I had neurosurgery and have been left to manage my way through the pain with my GP.

It's jaw-dropping when (professional/medical) persons from so-called 3rd world countries seem far more familiar with these issues & types of pain than our supposed 1st world professionals. Horrifying to be honest. Hard to feel safe, hard to trust, and becomes an enormous challenge to save up so much money to get either very little, or no results, and the 'professional' seems to be 'winging it'!

We all have to wait so long before we get help from someone who really knows what we go through.

No one ever seems sure who treats it so you tend to just get handballed. Dr sends you to dentist but when it's an inflammatory issue not mechanical dentist sends you back to the Dr who is clueless.

It has taken me over 40 years to get answers for my jaw pain.

Many treatment options - I was 17 when diagnosed and a good long term plan was never discussed with me. I am 25 now and improved, but still struggling. Seems to be a lot of short term fixes but no real 'whole body' approach or information about the long term impacts of treatment options

I found a lack of communication between the various medical/ dental specialties, including anaesthesia. A failure to discuss my daughter's condition satisfactorily with me (she has severe cerebral palsy) and some doctors were quite dismissive.

If specialists are going to refer patients to a pain management clinic they need to acknowledge all medications used including medical cannabis. As it has turned out the cannabis oil has been the game changer. Reduction or removal of many painkillers after years of additions, including Epilim, Lyrica, Panedine Forte and Tramadol.

It's hell. I'm on tegretol for the rest of my life and can't miss a day or pain is unbearable.... My teeth feel so bad but are in good condition but I feel like having them all ripped out daily but am advised I will still have the pain.

Of my own volition, I visited a GP, dentist, physiotherapist to attempt to treat the pain, and also underwent an MRI searching for a cause. This was all quite expensive and time consuming. I have a dental splint, got my eyes checked just in case, and receive regular physiotherapy to treat this pain, but not much has been overwhelmingly helpful except for physio. It has been really debilitating undergoing this pain and it has been kind of hard knowing where to go for help and advice.



Took a couple of neurologists and a pain spec before diagnosis  
Hemicrania continua, plus previous crps.

All I was offered was a dental splint. This made the pain so much worse and I was simply told 'you'll get used to it'. Extreme lack of understanding of what it is to have nerve pain.

In general Drs need a more wholistic approach and to learn to listen to their patients especially when they can access some resources for groups around the world.

This is life ending pain and no one knows what to do with you - you just get shuffled from one place to the next.

I use my osteo to help manage the pain and associated conditions are treated with medications from my rheumatologist.

Any possible solutions has little if any fundings. Was told one DHB had funding for two TMJ joint replacements each year at a cost of \$60,000 per side. Still living with severe degenerative arthritis in both sides with opiates as my only option for pain relief due to CKD. 3 OMS specialist later. If I had an accident that cause this it would be covered by ACC. Because it is the result of Acromegaly, no help for me.

I have now been diagnosed with Trigeminal Neuralgia, but it took months of pain and different treatments and medication before it was diagnosed. Thank goodness for my GP being on the ball and diagnosed what it was and getting me referred to a Neurosurgeon.

Ridiculous doctors and specialists try to push anti depressant medication on you. Woeful

When one practitioners' treatment doesn't work they simply stop seeing you.

Nobody seems to have standard training in TMJD. Occipital neuralgia is flippantly dismissed as a headache.

I had severe TMJD and was seeing a wonderful oral maxillofacial specialist at the dental hospital for over 7 years. Xrays and MRI's were showing that arthritis was eating away at my jaws and I was advised pain management due to the fact I was considered too young to have bilateral jaw replacement surgery. I was in my 30's and by 40 I was an inpatient at a pain rehab hospital to try to help manage the daily agonising pain. Finally after some 3D xrays were taken of my jaws, I was referred to a surgeon but only for assistance to try to slow down the damage being done to my jaws by arthritis. He immediately advised surgery stating: "You cannot live with this until your 60's". Prior to the surgeries, each time I saw the surgeon and he would feel my jaw joints he would shake his head and ask: "how are you managing to live with this pain"? given I took few painkillers. I thank him for advising I need more than just cortisone injected into the joints and for giving me back my quality of life by replacing the joints. I am now a crisis telephone counsellor which is something I could never have done prior to the surgeries. I suffer chronic pain in other parts of my body but no pain compares to that of TMJD and all that living with severely arthritic jaw joint involves.

No one will treat the pain until exploring all options. Which I understand, but I can't afford sleep studies and psychology and dental splints and specialist visits. So even though they all agree that I have fairly severe tmj, I can't afford an outcome.

Thanks for this post you have explained everything I have suffered for years.

Changing GPs helped. My surgeon and neurologist were fabulous in helping me.

I have TN and although my GP and neurologist are really good I am limited to meds which, due to insane

side effects, reduce me to an invalid. Further research into better treatments would be great. (Surgery is not an option for me). The local pain clinic is only interested in getting me off meds. Without meds the pain makes me suicidal, anything to stop the pain.

I have consulted all the above.

For years I was told 'it wasn't possible' or that I must be making it up. Finally I found Drs who know, understood & helped to treat without blaming me. We have all worked hard to improve my pain but more Drs need to know more about this type of pain, we aren't lying & it's not the same as other types of nerve pain.

Living with Trigeminal Neuralgia is very difficult & when presented with GP's or ED's who don't understand facial nerve pain and send you away with standard pain relief, that is proven not to work with TN, is devastating. It is very hard to verbally communicate how much pain you are in when having a bad flare up, & to be not believed by many healthcare professionals when your pain is well over the 10/10 threshold just because they have no real understanding of facial nerve pain is very, very difficult to hear.

Treated as a "headache" too often.

Too hard to access help sometimes. More education is needed.

I have trigeminal and occipital neuralgia. I was given a prescription from a neurologist and told I'd have to live with it. No follow up as I didn't have a nerve compression. 10 years on and I've developed coping mechanisms from Facebook groups and experimentation. Not great medical support and I get the third degree from Drs trying to get repeat prescriptions.

Difficult to explain this type of pain as there is no clinical evidence apart from presenting patients.

More GP awareness. Also awareness with Governing Bodies such as Centrelink.

My sinusitis causes numb and painful teeth as the nerves of the teeth are affected. I also have arthritis of the jaw and temporal area. Doctor put me on anxiety medication stating they could not help.

Pain management seems to be the only answer offered.

My dentist has a special interest in Orofacial Pain and is incredibly knowledgeable. I have Atypical Trigeminal Neuralgia and the neurologist who diagnosed me seemed to know very little about the connection between Orofacial Pain and TMJ yet for me, my TMJ, neck and shoulder issues are significant TN triggers.

Dental should be more accessible for those on low income, especially with chronic health conditions. I am on a waitlist for more dental treatment and partial dentures.

I have trigeminal neuralgia and live in excruciating pain.