

Trigeminal neuralgia: Imaging and the patient experience of Magnetic Resonance Imaging (MRI) of the brain: Findings from an on-line survey of patient experience of MRI imaging.

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# Acknowledgments

## Research assistants:

- Rebecca Orton <sup>a</sup> LLB (Hons)
- Clare Carolan DCR (R)

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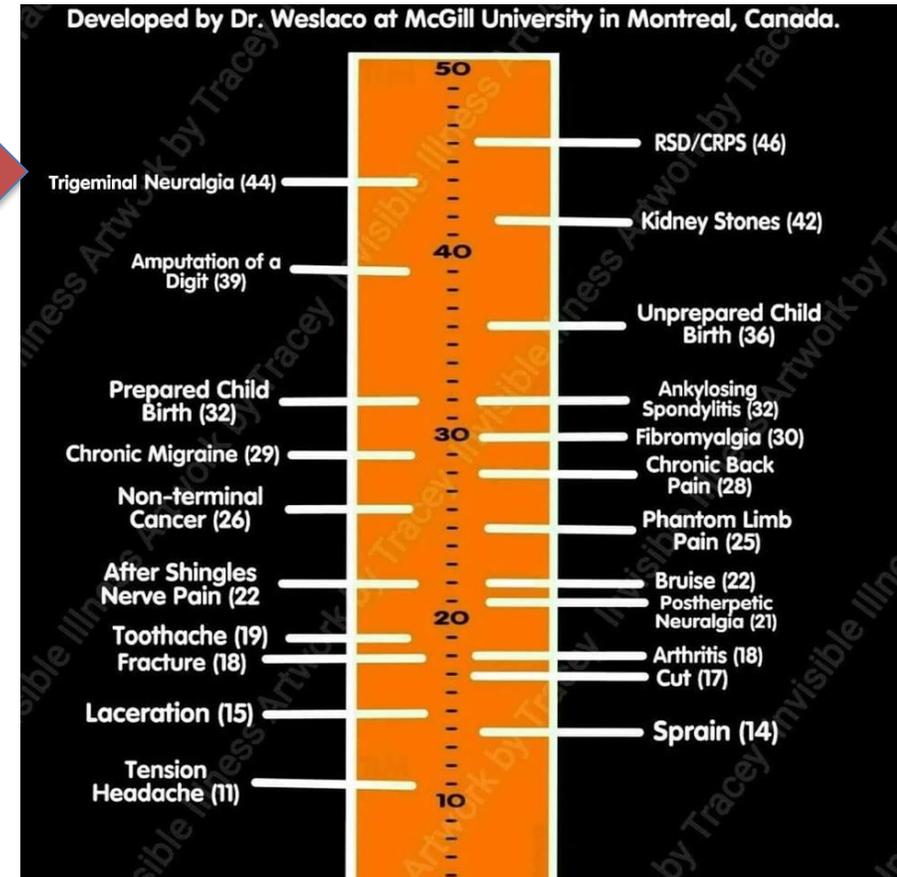
Thank you to Admins of closed Facebook group (Trigeminal Neuralgia – The UK's TN Facebook group) in order to advertise survey to members

# What is Trigeminal Neuralgia ?

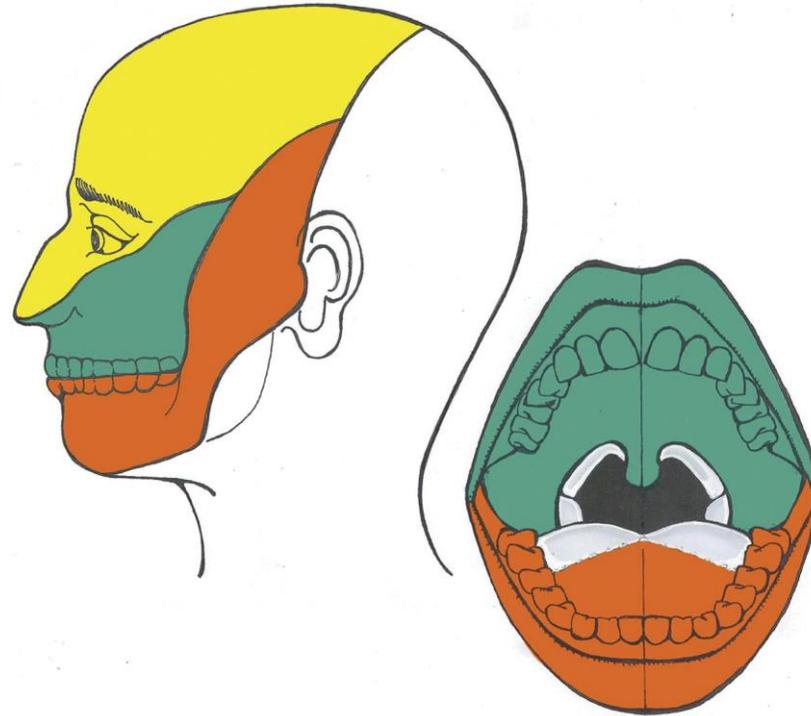
- Trigeminal neuralgia (TN) is often stated to be one of the most painful diseases known to man (Maarbjerg, 2015)
- The pain is intense and in classic TN lasts anywhere from a few seconds to a couple of minutes typically
- There are usually ‘trigger’ areas on a person’s face, depending on which branch of the nerve is affected, so again these can vary from person to person.
- This is known as the ‘trigger’ hypothesis, because the myelin sheath on the trigeminal nerve is damaged, often by vascular contact with the nerve as it exits to root area around the brain stem, the nerve fibres then become hyperexcitable



## McGill Pain Index



There are three branches (Trigeminal) and the areas of the face affected reflect which branch(es) are affected



# Why MRI?

- Patient's often require MRI imaging in order to rule out any other brain pathology, such as a tumour or multiple sclerosis.
- Additionally to identify if a blood vessel pressing on the trigeminal nerve which can be present in some trigeminal neuralgia sufferers.
- Typical sequences –
  - Ax T2 – whole brain.
  - Ax DWI – whole brain.
  - Ax CISS – through the posterior fossa.

# Why research this?

- Main author (JdW) tweeted about Trigeminal neuralgia awareness day seemed little or no awareness about the condition.
- Understandable as this is a fairly uncommon condition, prevalence of around 0.3% of the population (Fallata, 2017).
- The pain is often 'triggered' by a number of environmental events, including air blowing on the face and pressure on the face.
- I know that people with TN fear pain, really fear it....will try to avoid triggers.
- There is no literature around this condition in the radiography facing literature.
- Patient experience was important to capture; not just a technical review paper.
- There is nothing written from the patient perspective, and this was an opportunity to try and address this.
- Qualitative study; thematic analysis
- Ethical approval from University of Derby

# Questionnaire

## Demographic questions

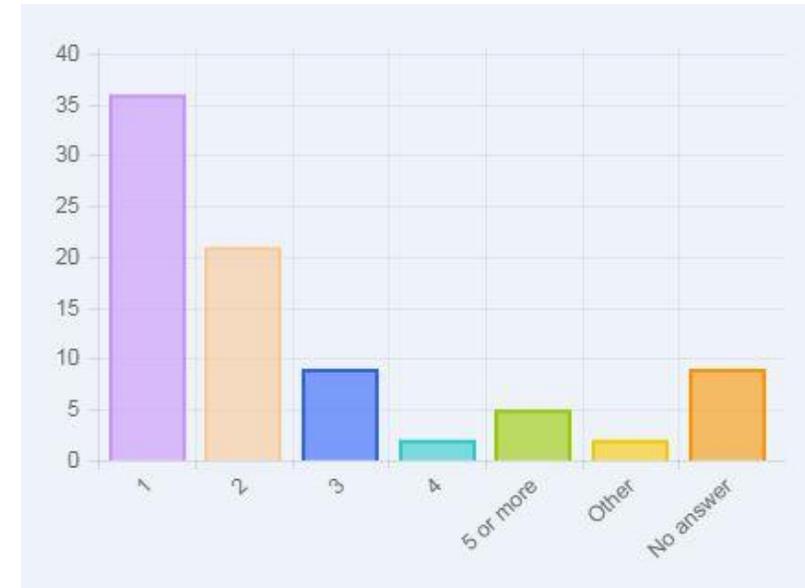
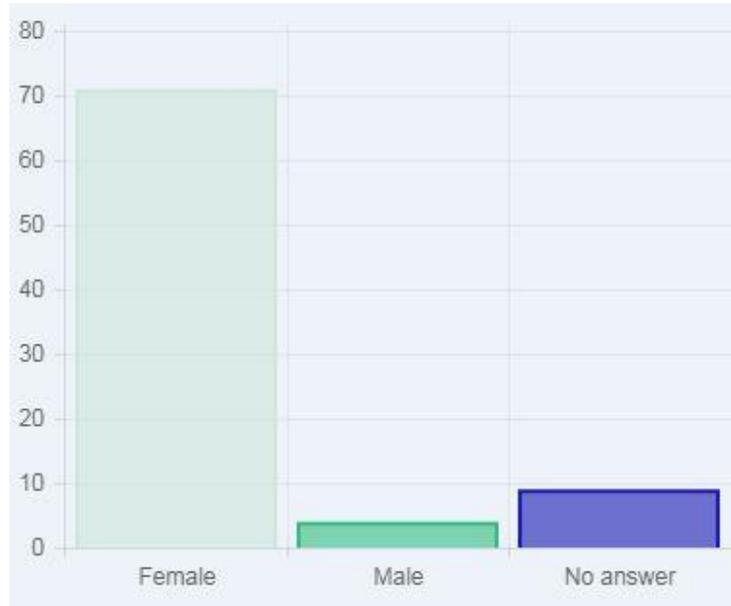
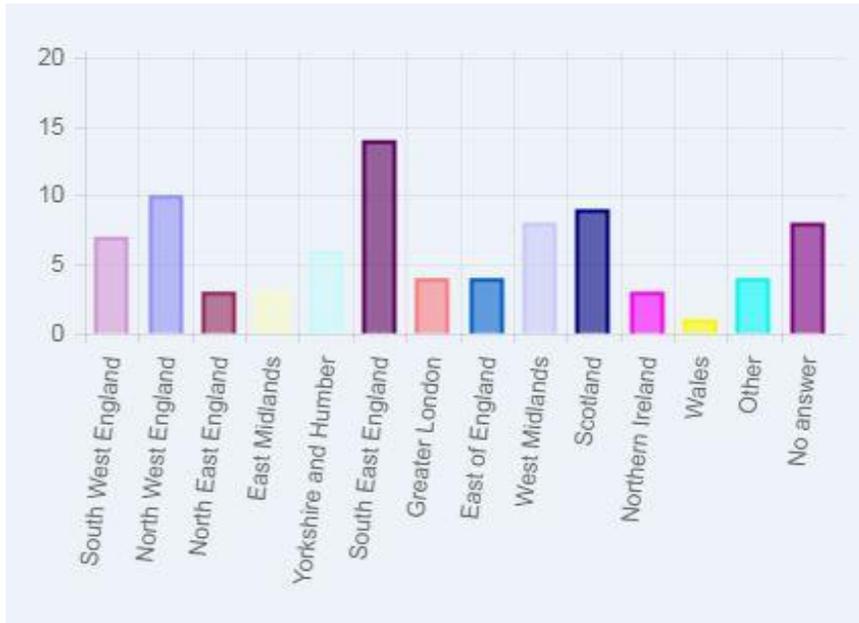
Questions inviting participants to leave **open text comments** were:

- How would you describe your experience of having an MRI brain scan?
- What made a positive difference or may have made a positive difference to your experience of having an MRI brain scan?
- If you were to have an MRI scan again, what would you like the radiographer (the person operating the scanner) to know about your condition?
- Is there anything else you would like a radiographer to know about your experience of having an MRI brain scan?

**Findings:** There is a lot of data – we'll discuss some of it here, but please ask for more details, or watch for details of academic paper (which hopefully will come from this!)

# Respondents

96 respondents

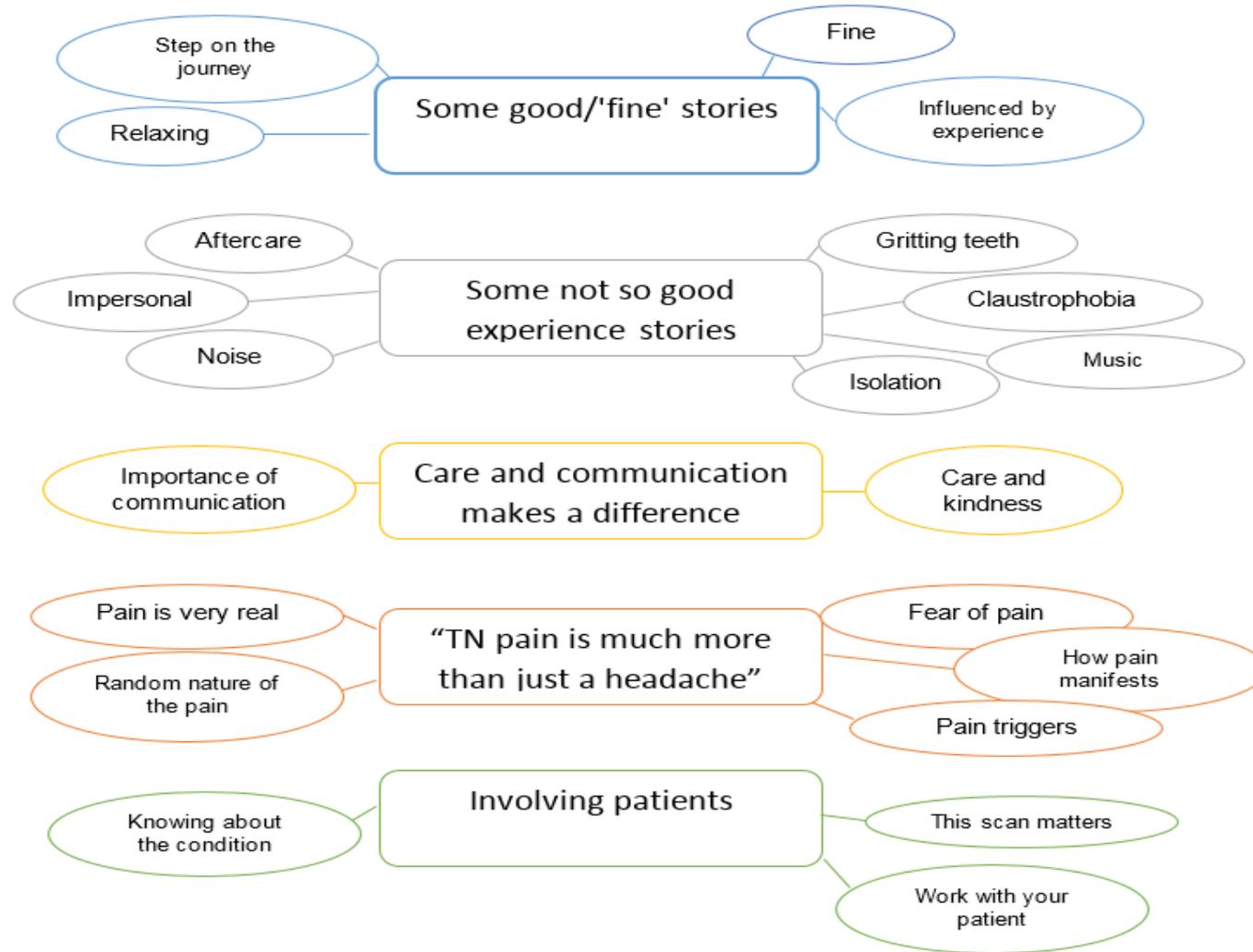


There is a female respondent bias

More than 1/3<sup>rd</sup> of respondents have had more than 1 MRI brain scan



# Themes



# It was fine....

Note: The R number against the quotes on the following pages is a respondent number

Reassuringly many patients (22) seem to indicate that the experience was 'fine' or they used the words 'manageable'.

*"It was fine"* (R5)

*"I found the experience quite calming and I wasn't at all anxious, even though I was in a confined space"* (R31)

Some even fell asleep:

*"I was quite relaxed and began to doze off on both occasions !"* (R12)

## But?

Some comments are caveated with comments which seem to indicate that the respondent is tolerating any discomfort or apprehension in order to get the scan completed. One respondent did seem to confirm this in a comment:

*"It was not the nicest thing but manageable due to it hoping to get help"* (R7)

# Being kind makes a difference !

## Staff attitudes/kindness/being nice

Patients do notice the kindness and it makes a difference:

*“The most positive thing about having the MRI scan was the Radiographer who was very nice and took all my worries away” (R8)*

And in this narrative the respondent is comparing experiences, and the staff made the difference:

*“This was my second MRI scan and was a much better experience to my first .... this was mainly because the professionals were quite good at explaining the process and what to do if I felt anxious at any stage”.*  
(R26)

# And communication matters....

## **Importance of communication**

Some patients felt very well informed during the scan, and this made a difference:

*“I liked the feedback during my scan -someone telling me how far through the process I am and everything is working out effectively”*  
(R22)

*“the radiographer was a very nice man who told me exactly what would happen”* (R8)

**But.....**

*“I don't like to make a fuss but a kind word or someone checking I was OK or realising I could have been in pain would have changed the experience”* (R21)

## But....Claustrophobia

Unsurprisingly, there was some mention of claustrophobia (or variations of spelling) in some respondent's answers, however only 5 talked about definitely being an issue for them:

*“Frightening. I am claustrophobic” (R37) they went on to note they “felt like they had been buried alive”*

and this respondent did indicate they felt they may need sedation if they ever require another MRI scan.

None of the respondents seemed to indicate they had abandoned the scan or needed to be medicated for the scan. It was good to see that a break was sometimes used to help the patient manage:

Breathing was often mentioned as a technique for ‘getting through’:

*“I had to have a break half way through but it was ok” (R20)*

*“I felt a bit Claustrophobic and trapped but told myself “just keep breathing nice and steady” (R5)*

## Those explaining a not so good experience described:

Isolation	Noise	Impersonal	Gritting teeth
<p>But some respondents noted that they felt quite isolated:</p> <p><i>“I would liked it if the radiographer every 10 minutes or so spoke to me, as you feel so alone in there with all that noise going on” (R49)</i></p>	<p>The noise of the scan was mentioned fairly frequently (18 times) and in some cases this the patient seemed unprepared for the noise:</p> <p><i>“It would have helped to be prepared about the noise and alarms”.(R3)</i></p>	<p>Feeling rushed is sometimes noted in the narratives</p> <p><i>“As if I was on a conveyor belt..” (R16)</i></p> <p><i>“it was very impersonal and busy..” (R28)</i></p>	<p><i>“I found it difficult but I knew it was important to enable a proper diagnosis”(R20)</i></p> <p><i>“I just gritted my teeth and stayed as still as I could”. (R21)</i></p>

Interestingly music was not always offered, and some comments on this would have made a difference

# PAIN

In virtually every patient narrative the word 'pain' was used; there was a tangible fear of pain, and that this is not just a symptom. This is **PAIN**.

It pervades and seeps into everything, some patients were in pain during the scan and therefore found it a difficult experience:

*"Very difficult as was in so much pain" (R1)*

The pain can have a dramatic effect on a person's life; Zakrzewska (2014) notes how TN pain has an "enormous psychological impact" (p1) but that this aspect is often overlooked in academic papers.

**It is therefore important it is recognised in these patient experience narratives.**

Zakrzewska JM, Padfield D. Psychosocial Aspects of Chronic Pelvic Pain The Patient's Journey Through Trigeminal Neuralgia. 2014.

## ***Pain is very real: There is a fear pain may not be taken seriously.***

Most importantly patients want the professionals they encounter to know that:

*“TN pain is much more than just a headache” (R1)*

*“...not assume that it is like severe tooth ache or bad headache” (R39)*

*“to realise TN is a genuine condition” (R31)*

*“some understanding of how painful it really is” (R24)*

The patient may also fear they are seen as ‘difficult’ because of the pain (or fear of pain), such as in this narrative:

*“I’m not being difficult the pain I’m suffering is excruciating and the slightest touch even sets it off.” (R1)*

# Fear scan may trigger pain

## ***Fear of pain***

Even if not in pain there is a fear that the scan may trigger pain:

*"I was worried that the process could trigger my pain" (R16)*

*"anything to do with my head/face is scary, as is excessive noise. Therefore reassurance that it couldn't trigger an attack would be v. helpful" (R16)*

## ***And if pain strikes.....***

Pain is so severe that a patient may not be able to even speak:

*"...you can't always talk through the pain to let them know"  
(R21)*

# ***Pain triggers***

For some patients the MRI scan did trigger pain, but even if pain was not triggered, **fear of pain** being triggered is usually present. Pain triggers are individual but this respondent summed the nature of pain triggers up nicely:

*“that pain can be triggered by touch, breeze, frown/smile/talking, that noise and stress can be triggers so tips about how to keep calm might help.” (R3)*

**Touch was a real concern** amongst several respondents, for example:

*“do not touch my head, be careful when putting the head positioner thingy on !” (R18)*

For some **noise can trigger** a pain attack:

*“Noise of the scanner set off my pain” (R18)*

It is important **to check triggers**, as this respondent noted that:

*“even putting ear plugs in could set it off” (R13)*

# Should radiographers know about TN?

*“I assumed they knew about my condition, what it was, how I was affected and other aspects of my condition” (R14)*

*“...thought they already knew anyway.” (R44)*

Some respondents found this **to be the case:**

*“They knew enough about TN to check if the position I was in and the machine itself was causing pain/making it worse” (R23).*

Some respondents expressed they would like staff to know more about the condition from a **diagnostics point of view:**

*“I would like them to know its trigeminal so they know what they are looking for in each individual's brain scan.” (R35)*

A few **did not think** it mattered if the radiographer knew specifically about TN

*“No, not necessarily. It's not relevant to the scan.” (R19)*

## ***Work with us***

It was very clear that the respondents **were expert in their own condition**, perhaps this is to be expected with a rare condition. Therefore, the patient is the best person to assess their triggers and how to manage those. **This scan matters**, so some time spent understanding the individual's needs comes across as appreciated. For example:

*“to know how many triggers we have and to work with us”* (R39)

*“That I might need to position my own head so that there is less risk of pain flare during the procedure”*. (R3)

*“Talk to the person frequently explain everything”* (R18)

# Aftercare

This seems a powerful narrative about the importance of noticing

“At the end of the scan I was feeling shaky and tearful from the pain and stress of coping with the pain while trying to hide it. I was just told that I could get changed and go. I remember three people chatting and laughing in a room off the main scanning room while I tried to compose myself and get changed. They didn't even seem to notice I was there even though there wasn't anyone else waiting. I think someone should have checked I was ok after the scan because it was obvious I was shaken but they didn't notice. I know it was over three years ago but it stayed with me”. (R21)

Aftercare is just as important as care given during the scan

# Thank you....

## **Questions we have**

- Do we teach enough about neuropathic pain at UG level or in Pg MRI?
- Could we maybe ask “is there anything about your condition it would be useful for me to know to make this scan more comfortable for you?”
- Do we approach each patient as an expert in their own condition? Their own body?
- Do we provide enough information about the MRI brain scan specifically?
- Why don't we always provide some music, or offer it?
- Do we communicate enough with patients during a scan ?
- Could we prepare patients better from point of view of noise ? Could patients bring their own, maybe better, earplugs (esp if noise is a trigger?)
- Do we teach noticing skills?
- What about aftercare? Is that good enough ?

**Maybe you have more questions.... Where do we go with future research ? Over to you !**

# Would you like to know more?

## About Trigeminal neuralgia

I would recommend the Trigeminal Neuralgia Association UK charity website

They have information for healthcare professionals and for public (and members), and have supplied some leaflets today if you are interested.

- <https://www.tna.org.uk/>

(Teal is the colour of TN awareness)

**Tweet me at @Juliede\_witt1**