

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Interventional procedures

Patient Organisation Submission Stereotactic radiosurgery for trigeminal neuralgia IP173/2

Thank you for agreeing to give us your views on this procedure or operation and how it could be used in the NHS.

When we are developing interventional procedures guidance, we are looking at how well a procedure or operation works and how safe it is for patients to have.

Patient and carer organisations can provide a unique perspective on conditions and their treatment that is not typically available from other sources. We are interested in hearing about:

- the experience of having the condition or caring for someone with the condition
- the experience of having the procedure or operation
- the outcomes of the procedure or operation that are important to patients or carers (which might differ from those measured in clinical studies, and including health-related quality of life)
- the impact of the procedure or operation on patients and carers. (What are the benefits to patients and their families, how does it affect quality of life, and what are the side effects after the procedure or operation.)
- the expectations about the risks and benefits of the procedure or operation.

To help you give your views, we have provided this template. You do not have to answer every question — they are there as prompts. The text boxes will expand as you type, the length of your response should not normally exceed 10 pages.

Please note, all submissions will be published on the NICE website alongside all evidence the committee reviewed. Identifiable information will be redacted.

About you	
1. Your name	██████████
2. Name of organisation	Multiple Sclerosis Trust
3. Job title or position	Head of Information and Engagement
4. Brief description of the organisation (e.g. who funds the organisation? How many members does the organisation have?)	<p>The MS Trust is a UK charity dedicated to making life better for anyone affected by multiple sclerosis (MS).</p> <p>The MS Trust is in contact with over 40,000 people affected by MS - that's people with MS, their families, friends and the health care professionals who help manage MS. Our core belief is that the best outcomes will come from well-informed people with MS making decisions in partnership with their specialist health professionals, and our aim is to support both sides of this partnership as much as we can. We provide expert information to help people with MS manage their own condition, and, uniquely, we inform and educate the health and social care professionals who work with them about best practice in MS treatment and care.</p> <p>We receive no government funding. We are not a membership organisation. We rely on donations, fundraising and gifts in wills to fund our services.</p>
5. How did you gather the information about the experiences of patients and carers to help your submission?	<p>(For example, information may have been gathered from one to one discussions with colleagues, patients or carers, telephone helplines, focus groups, online forums, published or unpublished research or user-perspective literature.)</p> <p>We have prepared this submission based on our experience of supporting people affected by MS at all stages of the condition. We speak daily to people who are dealing with issues relating to MS: coping with the impact of diagnosis, coping with physical, emotional and financial consequences of MS.</p> <p>For the purposes of this submission we have carried out additional research by surveying our MS community via social media specifically on trigeminal neuralgia and stereotactic radiosurgery.</p> <p>Trigeminal neuralgia can be a symptom of MS, affecting up to 6 in 100 people with MS, and becoming more common with age.</p>

Living with the condition

6. What is it like to live with the condition or what do carers experience when caring for someone with the condition?

Trigeminal neuralgia (TN) is a debilitating and very distressing condition for those who experience it and their carers and relatives. It is a severe nerve pain which can give stabbing or burning sensations down one side of the face. The pain comes on rapidly and, at least initially, lasts for seconds or a few minutes. Anything between 5 and 50 episodes can occur in a day.

The pain is sharp and most commonly described as an electric shock or lightening. It is particularly provoked by ordinary light touch activities such as eating, brushing the teeth, washing the face, and going out in the cold wind.

An attack can last for weeks or months and then disappear completely. These remission periods can vary from weeks to months but at present there is no predicting when it will go into remission.

“Trigeminal neuralgia. I have this today, I sensed its beginning late last night. My right side of my face can't be touched, it is burning, the skin is hypersensitive, and pain is beginning its usual path to my eye bone, and behind my right ear and jaw. It will progress over the next 24 hours to electric shock pains every few seconds” – Person with MS and TN, 2019

Trigeminal neuralgia has a huge impact on quality of life. It can result in loneliness and isolation as so many social events include eating, a task that becomes impossible during attacks. There is always a fear that it will strike unpredictably. Low mood, catastrophizing and depression are common, and sleep disturbance is frequently associated with TN.

To be in what has been termed ‘the most excruciating pain known’ or to witness it in a loved one is deeply distressing.

“I'm having a bout of trigeminal neuralgia-Please any help would be much appreciated- now missed 2 nights of sleep- nights are worse, but days aren't great either. It's a pain that truly wears me out through to my soul.” – Person with MS and TN, 2019

Trigeminal neuralgia in multiple sclerosis (MS) is particularly hard to manage. TN in people with MS is more likely to be severe and less likely to go into remission.

Management of TN in MS is made more complex by the other symptoms of MS, which include fatigue, neuropathic pain, bladder and bowel issues and

mobility problems. These can be worsened by the standard medications for TN.

“I’ve recently been told I have trigeminal neuralgia and the doctors have put me on 400mg of carbamazepine but they are making me feel awful. I am feeling dizzy and sick all day to the point I don’t want to get up the off sofa all day” – Person with MS and TN, 2020

By the time TN has been diagnosed, many people with MS have already had surgery.

“I understand the desperation and overdosing too. You would do anything to stop the pain. I went to the dentist and ended up getting 3 teeth taken out to see if it would stop the pain. Needless to say, it didn’t.” – Person with MS and TN, 2018

Reference: [www.msard-journal.com/article/S2211-0348\(19\)30261-5/fulltext](http://www.msard-journal.com/article/S2211-0348(19)30261-5/fulltext)

Advantages of the procedure or operation

7. What do patients (or carers) think the advantages of the procedure or operation are?

Stereotactic radiosurgery for TN is a non-invasive process. There is no need for a general anaesthetic or an incision. People with MS can find that surgery or other general anaesthetic procedures can trigger a relapse or worsening of their MS.

“My husband has had stereotactic surgery 6 weeks ago at Royal Hallamshire Hospital Sheffield. Brilliant experience for him and hardly any pain now since having it done but still on medication for another 2 months. They will then wean him off and see how he is. I know it can reoccur, it’s not a cure, but so far I’m just happy with the relief he is having at present and we know it can be done again” – Partner of a person with MS and TN, 2020.

People with MS may not be able to tolerate the standard medication options for TN, as they can result in MS symptoms worsening to the point that quality of life is seriously impaired. People with MS and TN often end up taking multiple medications in an attempt to balance their symptoms and side effects, and can spend a lot of time with their symptoms poorly managed and in pain.

“Decreasing the carbamazepine improved my mobility enormously however I was quickly reminded of the horrendous pain down the side of my face which once again brought me to tears! No wonder it’s dubbed the suicide syndrome!”
Person with MS and TN, 2019

“I think I’ve tried just about every combination of meds available. I am now on the highest dose of Gabapentin and amitriptyline. I also have oramorph and morphine tablets for breakthrough pain.”- Person with MS and TH, 2020

Disadvantages of the procedure or operation

8. What do patients (or carers) think the disadvantages of the procedure or operation are?

No disadvantages were communicated to us, except that it is not a permanent cure for TN.

Patient population
<p>9. Are there any groups of patients who might benefit either more or less from the procedure or operation than others? If so, please describe them and explain why.</p> <p>People with MS and TN need this procedure to be available as they may not be able to tolerate medication or have surgery without risking relapse or MS symptoms worsening.</p>
Equality
<p>10. Are there any potential equality issues that should be taken into account when considering this topic?</p> <p>Equality of access to NHS services is important. Living a long way from a service offering this procedure may mean that some people with MS may not be able to access it if they have difficulty with travel, public transport or otherwise.</p>
Other issues
<p>11. Are there any other issues that you would like the Committee to consider?</p> <p>No</p>
Key messages
<p>12. In no more than 5 bullet points, please summarise the key messages of your submission.</p> <ol style="list-style-type: none">1. People with MS tend to have particularly severe TN which is complex and difficult to manage.2. Stereotactic radiosurgery is non-invasive and people with MS and TN tend to recover from it better than invasive procedures.3. People with MS who have TN often cannot tolerate standard medications for TN, as they can worsen their other symptoms of MS.4. People with MS and TN need to have stereotactic radiosurgery as a treatment option.

Thank you for your time.

Please return your completed submission to jp@nice.org.uk