Royal College of Surgeons of England

ADVANCING SURGICAL CARE

Guidelines for the management of trigeminal neuralgia

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Contents

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Trigeminal Neuralgia Association UK (TNA UK)

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Introduction

Trigeminal neuralgia (TN) is a rare but devastating episodic, usually unilateral, electric shock-like facial pain.[1] TN pain is restricted to one or more divisions of the trigeminal nerve, with 3% having bilateral pain, mostly in those with multiple sclerosis (MS). TN pain is sudden in onset and typically lasts only a few seconds (2 minutes maximum). Patients may report their pain as arising spontaneously, although pain attacks can be triggered by innocuous light touch stimuli or movements.[2] Patients usually do not experience pain between attacks; although should they report additional continuous pain, in the same distribution and in the same periods as the sharp attacks of pain, they are considered to have TN with concomitant pain[3] (14-50% of patients have TN with concomitant pain)[4]; this concomitant pain can be mistaken as toothache. TN is classified into three categories: idiopathic TN occurs without any apparent cause; classical TN is caused by vascular compression of the trigeminal nerve root; and secondary TN is caused by a neurological disease, eg a tumour or multiple sclerosis.[2,3,4]

TN results in a significant negative impact upon quality of life and can lead to suicide.[5,6,7,8] TN can be misdiagnosed as a dental problem due to the presentation of pain and trigger points in the mouth.[9] Patients will often undergo unnecessary, sometimes irreversible dental treatment before the condition is recognised.[7,10] The referral of TN patients can also be problematic; general medical practitioners (GPs) often refer to general neurologists and dental surgeons often refer to oral and maxillofacial surgical teams, without guarantee that the secondary care teams have significant experience in the management of TN.[11]

A small subset of those presenting with TN (up to 10%) can have TN secondary to an underlying pathology such as a brain tumour, multiple sclerosis or vascular malformations, which will only be identified on neuroimaging.[10] A United Kingdom (UK) survey of 225 patients with TN who attended an outpatient facial pain clinic showed that prior to attendance: 42% had seen a dental/oral specialist (largest group being oral and maxillofacial surgeons - 32%); 8% had irreversible, unnecessary dental treatment; 37% had seen a neurologist and 19% had seen a neurosurgeon.[7]

Despite national guidelines[12] and international recommendations[13,14] on the management of TN only 54% of patients have been provided the recommended drug carbamazepine prior to attending a specialist service. Prior to referral, 75% of TN patients have used more than one medication, with 47% being issued 3 different medications, which are often ineffectively prescribed.[7] The available evidence would, therefore, seem to suggest that the diagnosis and initial management of TN is often inadequate, or inappropriate.

There is no evidence supporting the role of opiates/opioids in the management of TN.[14] Initial treatment with anticonvulsant medications eg carbamazepine, will often provide complete pain relief for TN.[1,14] The efficacy of anticonvulsants however, can diminish over time. Additionally, the significant side effect profile of anticonvulsants can lead to tolerance issues. Under such circumstances patients should be referred to a neurosurgeon to consider surgical management.[15] It is reported that TN patients can demonstrate cognitive impairment as a result of both their pain and medication side effects.[16,17,18] Discussions with neurosurgeons should therefore take place when pain is well controlled, in order to facilitate and validate the surgical decision-making process. The surgical management of TN can lead to long term, complete pain relief and cessation of all medications in some cases. For others, complications and recurrence can lead to refractory pain for which long-term medical and surgical management is required.[13,14] Not all TN patients require surgery and the timing of surgical procedure varies. Studies have shown TN patients express a preference for surgical management over medical management and, of those who received surgical management, 75% would have preferred earlier surgical intervention.[15,19]

Intended audience

This guideline provides information for hospital specialists and other healthcare providers who are involved in the diagnosis and management of TN eg GPs, dentists, pain clinics, oral medicine, oral and maxillofacial surgery, neurology and neurosurgery, so that informed and evidence-based discussions and decisions can be carried out with patients. Moreover, the guidance can be used by TN patients to help inform them about the management of their condition. A plain language summary is included for the benefit of patients, carers and healthcare professionals not familiar with TN (appendix A).

Statement of conflict of interest

The Faculty of Dental Surgery is funded by its fellows and members, and no contributors or reviewers were paid for their work on this guideline.

Aims and Objectives

The aim of this guideline is to address the need to improve the care of TN patients nationally, by establishing a clear care pathway for the management of both acute and chronic TN, using a multidisciplinary approach to care.

Development and evidence base

This guidance was developed in accordance with the existing internationally agreed trigeminal neuralgia guidelines,[13,14] and a recently published systematic review on the acute management of TN.[20] The recommendations in this guideline have been derived from these existing sources, with any caveats or divergent advice being cited separately. The guideline development group (GDG) employed a modified Delphi methodology (the guideline draft is circulated to the group, feedback is collated, before another draft is produced and circulated again for appraisal) to produce the guideline[21] – in order that a recommendation be included in the final guideline at least 90% of the GDG were required to provide approval. Moreover, the final guideline draft was only produced once all stakeholder commentary was received and reviewed by the GDG. Furthermore, the existing international guidelines and systematic review used a combination of the GRADE (Grading of Recommendations, Assessment, Development and Evaluations)[22] and American Academy of Neurology (AAN) classification scheme requirements for therapeutic questions[23] appraisal frameworks to help develop their recommendations. Wherever possible this guideline will indicate the strength of recommendation in accordance with GRADE. The GDG note that this guideline is similar to a TN care pathway produced by a Danish group in 2015[24] and a UK group in 2020.[25]

Guidance

Diagnosis

General considerations include:

- The diagnosis and management of TN is a complex process and requires a multidisciplinary team approach.[24,25]
- The patient should be assessed by a specialist who has experience in diagnosing and managing TN. The diagnostic process may require a review by a dentally qualified clinician eg general dental surgeon, oral surgeon, oral and maxillofacial surgeon or oral medicine specialist, should a primary dental cause for the pain be a possibility.[24] The diagnosis of facial pain is almost exclusively reliant on the pain history,[1] hence time should be taken to actively listen to the patient's narrative and elicit a thorough history.[26,27]
- Should a diagnosis of TN be suspected in the primary care setting, it is reasonable to expect a GP, potentially in collaboration with a general dental surgeon, to initiate medical treatment, and concomitantly refer to a specialist service for a definitive diagnosis, investigations and further management.
- 'Red flags' that may necessitate a more urgent referral to specialist services include:[28] sensory or motor deficits, deafness or other ear problems, optic neuritis, history of malignancy, bilateral TN pain, systemic symptoms (eg fever, weight loss) and presentation in patients aged under 30 years.
- Patient related outcome measures (PROMS) should be employed at baseline and again at follow up (appendix B) . Currently, there is a wide range of different TN outcome measures, and work is underway to determine the most appropriate TN outcome set.[29]
- Patient information leaflets, copies of clinic letters with a written diagnosis and management plan, pain diary and online resources should be provided to patients/carers (appendix C).

Investigations

- The expectation is that TN imaging will be conducted in the specialist setting. The group recommends that ideally the reporting of TN imaging be conducted by a radiologist with a special interest in TN, and imaging may benefit from an assessment by a neurosurgeon with a TN interest; in keeping with existing recommendations, the radiologist, ideally, should be 'blinded' to the side of the pain.[24,30]
- Magnetic resonance (MR) imaging of the posterior cranial fossa - combination of two high-resolution sequences: 3D T2-weighted, 3D TOF-MRA (the aim of imaging is to identify any underlying pathology and determine if there is a neurovascular compression). The working group acknowledge recent international guidance which recommends against the use of intravenous contrast as routine,[31] and suggests that non-contrast studies will be sufficient for the majority of TN patients. Moreover, the remainder of the brain should be assessed with standard MR diagnostic sequences to assess for demyelination **[strong recommendation]**.
- Neurophysiological testing – should MR be contraindicated then testing of trigeminal reflexes (if available) may be employed as an alternative approach to help to distinguish secondary TN (ie associated with underlying pathology eg tumour, multiple sclerosis) from primary TN **[strong recommendation]**.
- Computed tomography (CT) - should MR be contraindicated, and neurophysiological testing be unavailable then CT can be used as an alternative form of imaging to identify underlying pathology;[32] however, the stronger and more up-to-date evidence prefers MR and neurophysiological testing.[13,14]

Medication

GPs in collaboration with a dental surgeon as appropriate, can initiate first line medication treatment for TN, while concomitantly referring to a specialist service. Once a definitive diagnosis of TN has been made by a specialist, it is expected that the GP will continue providing any medications with support as required from the specialist team. The group acknowledge that local prescribing formularies may potentially restrict which TN medications can be prescribed by a GP. Under such circumstances, we recommend liaison between the specialist team, GP and local medicines management committee, in order to ensure that patients are adequately supplied with the appropriate medications.

The medications used for TN must be taken on a regular basis in order to maximise their effect. However, once a remission period is noted i.e. no pain for at least 4 weeks, then the medication can be slowly tapered down and stopped. Should there then be a recurrence of pain the medication should be restarted and gradually escalated upwards to the lowest effective dosage; with this in mind it would be prudent for patients and GPs to ensure that the patient always has a ready supply of medication. Some patients are so fearful of a return of pain that they may reduce dosage, but do not fully stop their medications. Opiates/opioid medications are not indicated in the management of TN.[14] The use of pain diaries (patients chart daily pain activity against medication dosage) can be helpful to guide patients and clinicians.[33] Patients value medicines information tailored to their condition, although they don't wish medication leaflets to be a substitute for discussion with their clinician about their medication options.[34]

There have been very few clinical trials for TN medications, and hence the calculation of the numbers needed to treat (NNT) and the relative risk (RR) of the medication being effective (RR score >1 likely to be effective) are only possible for carbamazepine.

Comprehensive guidance on the medications listed in this guideline, including potential side-effects, interactions and dosing advice, can be found in the British National Formulary (https://www.medicinescomplete.com).

First line medications

(GPs and specialists can prescribe):

- **Carbamazepine** - therapeutic range is normally between 800mg – 1200mg total daily dose split over 4 separated doses; modified release and liquid forms are also available. Recommend HLA-B*1502 allele testing in individuals of Han Chinese or Thai origin (risk of Stevens-Johnson syndrome in presence of HLA-B*1502 allele). NNT is 2 (95% confidence interval (CI) 1-2) and RR is 5.87 (95% CI 3.58 to 9.61) **[strong recommendation]**
- **Oxcarbazepine** – alternative should there be medication interaction issues with carbamazepine. Therapeutic range is normally between 1200mg – 1800mg total daily dose split over 4 separated doses. Recommend HLA-B*1502 allele testing in individuals of Han Chinese or Thai origin (risk of Stevens-Johnson syndrome in presence of HLA-B*1502 allele). Consider monitoring of plasma sodium concentration in patients at risk of hyponatraemia (hyponatraemia tends to be dose related). **[strong recommendation]**

Alternative or adjuvant medications

(specialists only to initiate; GP can offer on repeat prescription with specialist advice):

Should a medication be ineffective, then another adjuvant medication may be added; however, there is little evidence assessing this approach.

- **Lamotrigine** - can be used in combination with carbamazepine (potential interaction - lamotrigine may increase the concentration of carbamazepine and carbamazepine decreases the concentration of lamotrigine)/oxcarbazepine or as monotherapy. Recommend gradual dose escalation up to a maximum of 200mg twice daily **[weak recommendation]**.
- **Baclofen** - can be used in combination with carbamazepine / oxcarbazepine; may be useful in patients with multiple sclerosis who are already using it for spasticity. Therapeutic range is normally between 40-80mg total daily dose split over 4 separated doses **[weak recommendation]**.
- **Gabapentin** - can be used in combination with carbamazepine/oxcarbazepine or as monotherapy. Therapeutic range is normally between 900-3600mg total daily dose split over 3 separated doses. Gabapentin is now a class C controlled drug **[weak recommendation]**.
- **Pregabalin** - can be used in combination with carbamazepine/oxcarbazepine or as monotherapy. Recommend dose escalation up to maximum of 300mg twice daily. Pregabalin is now a class C controlled drug **[weak recommendation]**.

Acute Adjuvant medications:

The previously listed anticonvulsants may take several days to take full effect; therefore, the addition of a quicker acting adjuvant treatment can be considered while the anticonvulsant takes effect.

Dentists, GPs and specialists can prescribe:

- **Lidocaine** - can be used acutely as an adjuvant to systemic medications should there be a defined 'trigger point'[20]:
  - Lidocaine 10mg per actuation nasal spray – 2 sprays into the nostril on the affected side (when pain is maxillary) as required **[strong recommendation]**
  - Lidocaine 5% ointment – applied directly to trigger point on face or inside mouth as required **[weak recommendation]**
  - Infiltration/block anaesthesia to trigger point (provided by dentally trained clinicians) - Lidocaine 2% 1:80 000 adrenaline; can consider combination with a longer acting agent eg bupivacaine, ropivacaine **[weak recommendation]**.

GPs & specialists can prescribe:

- **Sumatriptan** – in cases where there is no defined 'trigger point', sumatriptan can be used acutely as an adjuvant to systemic medications; 6mg subcutaneous injection.[20] **[strong recommendation]**.

Specialists can administer:

- **Botulinum toxin type A** - there is weak evidence that botulinum toxin may reduce pain intensity when used alongside other systemic drugs. There is no consensus on the dose or method of administration. Due to the delayed onset of action, botulinum toxin type A should only be considered for the medium-term management of TN[20] **[weak recommendation]**.

Should the previously listed adjuvant acute treatments be ineffective then the following could be considered (specialists only to administer):

- **Lidocaine infusion** – 1.5mg/kg[35] intravenous infusion over 1 hour (hospital admission with full monitoring; in 2020 the UK lidocaine infusion safety group published a recommendation for a reduced dosage of lidocaine (from 5mg down to 1.5mg/kg) subject to a review of efficacy)[20] **[weak recommendation]**.
- **Fosphenytoin** – 15mg/kg intravenous infusion (hospital admission with full monitoring)[20] **[weak recommendation]**.
- **Phenytoin**[36] – 10mg/kg intravenous infusion (hospital admission with full monitoring).

Surgery

Owing to the irreversible nature and potential risks of surgical procedures, it is important to ensure that prior to embarking on surgical management, all patients are assessed and diagnosed by a clinician with experience in the diagnosis and management of TN and provided with information about potential surgical procedures. The available evidence suggests that approximately 25-40% of patients will opt for neurosurgery within 2 years of referral to specialist centres.[24,25,37] Therefore, it is crucial that all TN patients have access to a neurosurgeon as part of their care pathway. There is no evidence to determine the best timing of surgery in the management of TN. However, surgery may offer the best long-term pain control outcome for many TN patients. Therefore, one should consider early referral to a neurosurgeon so the patient can have a discussion about possible surgical options. Potential criteria for a patient opting for surgery include – the use of a wide range of medications with reduced efficacy, poor tolerability of medicines, or significant negative impact of the condition upon quality of life.

Based on low quality evidence, but substantial clinical experience, it is **strongly recommended** that microvascular decompression (MVD) is employed ahead of stereotactic radiosurgery in TN patients with a neurovascular compression, who are willing and fit enough to undergo posterior fossa surgery. Similarly, a **weak recommendation** is given that MVD could be considered preferentially over neuroablative treatments, particularly if a definite neurovascular compression is present.

Table 1 provides a summary of the evidence base for surgical outcomes in TN. Surgical discussions should be supported by providing TN patients with written information on the procedures, including details on the possible side effects of surgery, and how to manage postoperative complications.

Table 1 Summary of surgical outcomes in TN (derived from Bendtsen et al. 2019)[14]

Intervention	No. of studies	Total number of patients	Mean/median follow up (years)	Pain free at follow up (%)
MVD	21	5149	3-10.9	62-89
Stereotactic radiosurgery	8	1168	3.1-5.6	30-66
Radiofrequency thermocoagulation	7	4533	3-9.3	26-82
Balloon compression	5	755	4.2-10.7	55-80
Glycerol rhizolysis	3	289	4.5-8	19-68
Internal neurolysis	1	26	3.6	72

Following completion of surgery, TN patients should be provided with a slow dose reduction regime for their pain medication, coupled with information regarding short term postoperative complications that may require urgent review e.g. cerebrospinal fluid (CSF) leak. Moreover, all TN patients should be reviewed at six weeks postoperatively by the neurosurgeons. More frequent, or longer-term review may be indicated if surgical complications occur. Following neurosurgical procedures, it should be expected that most TN patients will no longer require pain medication.

- **Microvascular decompression (MVD)** - should be considered in those patients with neurovascular compression on imaging, and who are fit to undergo a general anaesthetic. MVD has a mortality of 0.1%, can be associated with stroke, CSF leak, and a less than 5% risk of ipsilateral hearing loss. Furthermore, an MVD on average involves a 4-day inpatient stay; should there be a resultant CSF leak, then this may prolong the stay, or require a re-admission. Some neurosurgeons will carry out internal neurolysis ('nerve combing' – the fascicles of the trigeminal nerve are longitudinally separated but not divided, in order to release the scarring between the nerve bundles)[38] if no vascular compression is found at the time of the surgery. This situation is more likely for those patients with equivocal preoperative MR findings of a vascular compression. Internal neurolysis results in the same complications as MVD, but with a higher risk of sensory change after surgery; hence the consent process should include this in the discussions with the patient.
- **Percutaneous neuroablative procedures at the Gasserian ganglion level** – includes radiofrequency thermocoagulation, balloon compression and glycerol rhizolysis. These procedures are performed under general anaesthesia with imaging guidance, and usually involve an overnight stay. In view of the fact that they are ablative procedures (involve a degree of damage to the nerve) they very often will result in a change in facial sensation. Should the corneal reflex be lost, patients are informed to check their eye daily for redness and are encouraged to wear glasses when they go outdoors, especially if it is windy. Neuroablative treatments should be the preferred surgical intervention if MR imaging does not demonstrate any neurovascular compression and medical management is insufficient. There is insufficient evidence available to provide any recommendations between the various neuroablative procedures. There are some observational data suggesting that radiofrequency thermocoagulation (RFT) may offer higher rates of complete pain relief than glycerol rhizolysis, however, they are more likely to have complications (primarily numbness of varying intensity and extent). Anaesthesia dolorosa (numbness combined with persistent nerve damage pain) is a rare, but debilitating side-effect of TN surgery – it is most likely to occur after radiofrequency thermocoagulation (approximately 6 patients in every 1000 after RFT).[14]
- **Stereotactic Radiosurgery (SRS)** – radiosurgery for TN unlike other surgical interventions is minimally invasive, does not require sedation or general anaesthesia and is typically performed as a day case procedure. SRS is considered a primary alternative to the invasive surgical techniques[39] and has been found to be safe according to national guidelines.[40] As of 2020, the NHS has only commissioned two SRS centres for TN – the Royal Hallamshire Hospital in Sheffield and the National Hospital for Neurology and Neurosurgery in London.
  - SRS is a minimally invasive neuromodulative single session procedure, utilising focussed radiation which targets the trigeminal nerve with high precision.[41,42] The pain-relieving effects of this treatment are not immediate (different to the ablative surgical procedures); the time to pain relief is typically between 1 and 3 months. SRS is therefore not a suitable technique for acute TN crisis management.

  - The best outcomes for SRS are achieved in the patient group with classical TN,[39] patients without previous surgical intervention[43,44] and patients who are treated within 3 years of onset of the neuralgia.[45] However, the technique can be utilised to treat TN patients with recurrent pain following the use of other surgical techniques as well as in the treatment of multiple sclerosis (MS) or skull base tumour related to TN; the treatment outcomes in such cases are generally less favourable when compared to classical TN treated with SRS.
  - The success of SRS in the treatment of TN is dose dependent.[42] Pain recurrence is more frequent following SRS than after MVD. As with other ablative procedures, SRS has a risk of side effects eg numbness, reduced blink reflex, dry eye and, rarely, anaesthesia dolorosa. The side effect profile depends closely on the radiation dose and the anatomical site where the nerve has been targeted.[39] Should SRS be repeated for pain recurrence, a significantly lower dose of radiation must be employed, otherwise significantly higher rates of post treatment numbness have been found; resultant deafferentation pain (nerve damage pain), combined with the TN pain, could then become a problem.
- **Peripheral procedures** - these procedures involve treating the terminal branches of the trigeminal nerve, and hence depend on accurate assessment of which nerve branch is acting as the trigger area. The relevant nerve branch can then either be injected with alcohol, or surgically exposed and treated with cryotherapy or neurectomy. Most of these peripheral procedures can be carried out under local anaesthesia and do not require the patients to be medically fit for surgery. There are no long-term longitudinal studies relating to these peripheral procedures; the available evidence comprises of a few old, low quality case series.[14] Furthermore, it is difficult to compare the results of such peripheral techniques with other procedures such as MVD or Gasserian ganglion surgery due to variability in outcome measures and data analysis.[14]

Non-medical and non-surgical support

It is important to acknowledge that in addition to suffering from pain, TN patients will often have other pain-related disabilities, such as anxiety and depression.[46] Although the evidence for clinical psychology benefiting chronic pain management is well established, the currently available evidence for TN is still weak.[25,37,47] Pain management programmes for TN allow patients: to meet fellow TN patients, develop coping strategies for pain flare-ups, and cope better with their pain condition. Furthermore, there is some weak evidence to suggest that a telephone consultation service with a pain management clinical nurse specialist prescriber has been well received by TN patients; whereby the patient makes contact with the nurse, who assesses the patient and recommends changes to medication management via liaison with the patient's GP.[37,48] Therefore, it could be suggested that such programmes may reduce the reliance of TN patients on emergency departments and GPs for their pain condition. Moreover, the evidence suggests that TN patients report a need for the support and advice that they can obtain from support group volunteers who understand the needs of this community, coupled with email helplines, web-based forums and national meetings. Although the currently available evidence is weak, it is recommended that TN patients have access to pain management clinical psychologists, pain management nurse specialists and be signposted to the Trigeminal Neuralgia Association UK support group.[49] (appendix C)

Appendix A:

Plain Language Summary:

Introduction

Trigeminal neuralgia (TN) is a very severe, electric shock-like facial pain. TN involves the trigeminal nerve, which carries sensory information to the brain from the face and mouth. TN pain starts suddenly and usually only lasts a few seconds. TN pain is often triggered by light touch or movement of the face or mouth. For many people, the pain is felt in or around the mouth, which may be mistaken for toothache. As TN pain and dental pain can be similar, unnecessary dental work can be carried out. Once diagnosed with TN, patients can be prescribed the anticonvulsant medication carbamazepine (an anti-epilepsy medication) – which can stop, or at least significantly reduce the pain. Surgery is possible for TN and, depending on what is found them on head scans will determine what type of surgery may be offered.

This guideline aims to improve the quality of care for TN patients by providing information for healthcare workers on how best to diagnose and treat the condition. In addition, the guideline can be used by patients to help them understand how their condition can be diagnosed, and what their treatment options are. The guideline has been produced by a panel of specialists, and includes information taken from scientific publications and current international TN guidelines.

Diagnosis

In view that dental pain can present like TN, some TN patients may require to be examined by a dentist before their TN diagnosis is confirmed. Patients who have suspected TN should be referred to a specialist who is experienced in working with TN patients. Patients should be asked to complete ‘outcome measures’ (special questionnaires) before and during treatment, as this will help to determine if the condition is improving following treatment. Patients should also be given patient information leaflets about their condition and treatment.

Investigations

Patients diagnosed with TN should be considered for an MRI head scan (magnetic scan), as it can help to decide the type of surgery that can be offered and helps to rule out other causes of the pain eg tumours. Other types of investigations may be available if MRI is not possible, such as nerve tests and CT scans (x-ray scan).

Medication

Patients are encouraged to consider slowly reducing and even stopping their medication when their pain has gone for at least 4 weeks; they can slowly start it again if the pain returns. The use of pain diaries is encouraged as they may allow the patient and doctor to work out if the medications are useful. Information leaflets may be helpful for patients and doctors.

The first-line medication to be prescribed for TN is the anticonvulsant medication carbamazepine, while oxcarbazepine is an acceptable alternative. Other anticonvulsant medications and some injection treatments can also be considered, although it is recommended for specialists to start such treatments. Some patients whose pain is often triggered by a sensitive area of the face or mouth may benefit from an anaesthetic injection from their dentist, or application of an anaesthetic ointment or spray. Pain killer medications, such as morphine & codeine, are not effective in the management of TN.

Surgery

It is important to ensure that before considering surgery, the diagnosis of TN has been confirmed by a specialist who has experience with TN. Surgical treatment options can help to stop the pain and can be an alternative to medication treatment; the options should be discussed between the patient and a surgeon as early as possible. There are several different surgical treatments for TN – microvascular decompression (surgery that moves a blood vessel pressing on the nerve), or other procedures that involve damaging the nerve to stop the pain eg injection around the nerve, heating the nerve, or targeting it with focussed x-rays (radiosurgery). Surgical procedures for TN can cause a range of possible side effects, including numbness of parts of the face.

Non-medical and non-surgical support

TN can have a significant impact on someone's life, and it can affect their health and mental wellbeing in a number of different ways. An integrated and multidisciplinary approach to care can support someone to access the right services and information to meet their own personal needs and reduce unnecessary use of emergency health services. TN patients can suffer from anxiety and depression as a result of their pain, and they should have access to psychological therapies to help them manage their mental health and wellbeing. Specialist pain nurses can support TN patients with their medication and pain management strategies. Patient support groups such as the Trigeminal Neuralgia Association UK (TNA UK) can allow patients to discuss their problems with people who have also experienced TN and get access to information and education on the condition.

Appendix B:

Examples of PROMS that may be suitable for TN are listed below:

Brief Pain Inventory

https://www.mdanderson.org/research/departments-labs-institutes/departments-divisions/symptom-research/symptom-assessment-tools/brief-pain-inventory.html

Penn Facial Pain Scale

Symonds T, Randall JA, Hoffman DL, Zakrzewska JM, Gehringer W, Lee JY. Measuring the impact of trigeminal neuralgia pain: the Penn Facial Pain Scale-Revised. J Pain Res. 2018 Jun 5;11:1067-1073. doi: 10.2147/JPR.S152958. eCollection 2018.

Hospital Anxiety and Depression Scale

https://eprovide.mapi-trust.org/instruments/hospital-anxiety-and-depression-scale#languages

Appendix C:

Patient and clinician support:

Trigeminal Neuralgia Association UK (patient support and information)

https://www.tna.org.uk/

The Brain & Spine Foundation (patient support and information)

https://www.brainandspine.org.uk/our-publications/booklets/face-pain/

The Ottawa Personal Decision Guide (health-related decision aid for patients)

https://decisionaid.ohri.ca/decguide.html

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