Radiosurgery for trigeminal neuralgia

Information for patients
Stereotactic Radiosurgery
What is trigeminal neuralgia?

Trigeminal neuralgia is a sharp shooting pain in the face which may be triggered by activities such as eating or talking. When severe, it can affect many of the activities of normal daily living.

In most cases (so called primary trigeminal neuralgia) there may be no clear structural cause for the pain, although in some individuals a blood vessel may be pressing upon and irritating the nerve. More rarely (secondary trigeminal neuralgia), the pain is secondary to another disease or process, most commonly multiple sclerosis.

What options do I have?

- **Medication** - many patients find that their pain can be controlled with tablets, most commonly Carbamazepine. A proportion of patients, however, develop unacceptable side-effects on the medication used, and so wish to consider other options.

- **Open surgical exploration** - this involves an operation, under general anaesthetic, to explore the trigeminal nerve where it leaves the brain. This may be the best option for a nerve that is being compressed by a blood vessel as its removal may provide a lasting cure from the trigeminal neuralgic pain. If there is no blood vessel found then the nerve may be partially cut to alleviate pain but this will cause a degree of numbness.

This procedure can achieve pain relief in perhaps 80% or more of patients. However, it is a major surgical operation with a small risk of serious complications, including stroke or even death. If you choose this option, your surgeon will discuss the risks with you in detail before you consent to the operation.

Despite the risks, it may be the treatment of choice for fit patients who have a blood vessel compression.
• **Percutaneous needle techniques** - Under a general anaesthetic, a needle is passed through the face, using X-ray guidance, into the trigeminal nerve. The needle is then used to damage the nerve by either heating or cooling it, injecting alcohol into it or even compressing it. The main shortcoming of this technique is that it causes facial numbness at the same time as giving pain relief (and so is unsuitable for pain around the eye). The pain generally recurs, although relief may be achieved for two years or more. It does require a general anaesthetic where the patient may be woken part way through the procedure to check that the right part of the nerve is being numbed.

• **Peripheral procedures** - a painful section of the nerve can be numbed in and around the gums which may be done under local or general anaesthetic. This can offer a useful stop-gap in patients experiencing acute pain but again this is only achieved with numbness and the effects usually last months.

• **Stereotactic radiosurgery** - this is a specialist technique available in Sheffield which is carried out under local anaesthetic with the patient awake throughout the whole treatment process. It is sometimes referred to as Gamma Knife radiosurgery, and since 2000 we have been treating significant numbers of patients with trigeminal neuralgia in this way. The early results of this are such that we are increasingly being asked to see and advise patients with trigeminal neuralgia about radiosurgery. To date we have treated more than 730 patients with trigeminal neuralgia.

**Treatment with the Gamma Knife**

This is not a knife in the conventional sense and the treatment does not involve anything being cut. During the treatment a high dose of radiation is delivered to the trigeminal nerve.
The Gamma Knife works by focusing beams of gamma radiation on the target area. It has the ability to treat a very tightly defined target area without affecting any surrounding tissue.

Gamma Knife surgery is used exclusively for the brain, head and neck.

**Success rates**

The effects of radiosurgery appear to be delayed, in that pain relief occurs over a two to three month period and some patients have increasing improvement after this. It is advisable to continue with your medication after treatment until improvements occur. The procedure appears to be effective in about 80% or more of patients with primary trigeminal neuralgia. However, patients who have had multiple previous treatments seem to fare less well but will show improvement, although the benefits are less predictable.

Similarly if the trigeminal neuralgia is secondary to another underlying disease, whilst radiosurgery may help with the pain control, again the benefits are less predictable.
How many times do I have to come to Sheffield?

Most patients are seen in a specialist Trigeminal Neuralgia Radiosurgery clinic to verify the diagnosis and explore all treatment options. As radiosurgery is minimally invasive, does not require a general anaesthetic and appears so safe, patients are increasingly being referred to us for this treatment. Many of these patients have previously undergone significant other therapy, or other treatment options have effectively been exhausted.

We must seek your consent for any procedure or treatment beforehand. Staff will explain the risks, benefits and alternatives where relevant before they ask for your consent. If you are unsure about any aspect of the procedure or treatment proposed, please do not hesitate to ask for more information.

We plan only one treatment and this may involve a stay of up to two nights. Your accommodation whilst at the hospital will be discussed with a radiographer at your consultation.

When do I have to arrive at the ward?

You will be advised to arrive at the admission ward around midday. You will receive, in the Information pack, a list of nearby hotels and bed and breakfast accommodation.

What will happen on that day?

A nurse will meet you and show you around the ward. In the afternoon you will meet with the radiosurgery team who will take your history, check you for general medical problems (if this was not done at your clinic appointment) and will prescribe any additional medication necessary.

Most radiosurgery patients are prescribed a short course of Dexamethasone and Ranitidine. These will be fully explained to you
when you attend. It is usual for patients to continue with their own medication whilst undergoing radiosurgery. We may also require blood tests in preparation for treatment day.

You will have a chance to meet the Therapy Radiographer who will go over the procedure with you. You may also see the medical staff (if necessary) who can give further explanation about the procedure, and answer any questions you may have.

He/she would also ask you to sign your consent form if you did not complete this at your outpatient appointment.

**What will happen on treatment day?**

We need to target the nerve precisely. In order to guide us, we use a metal frame as reference. On the morning of the treatment, you will be taken to the X-ray department where one of the medical staff will apply the frame. This involves giving you four local anaesthetic injections into the scalp (two in the forehead and two in the back). When the area feels numb, four screws will be tightened to hold the frame rigidly to the skull.

This causes pressure but this feeling wears off after a few minutes. There is no drilling involved and we do not need to remove any hair. You will have the frame attached for the rest of the day, as all measurements are taken from this reference.

You will be taken to the MRI scanner to have images taken. You may be familiar with these from previous experience. Next the radiographer will take you to the Gamma Knife. There you will wait for the treatment plan to be ready. This may take an hour or two. When the plan is completed, the radiographers will carry out the treatment.

You are welcome to have a family member with you all day if this would make you feel more comfortable.
For patients who are unable to have an MRI scan (for reasons like pacemakers) we have other techniques to image and identify the trigeminal nerve.

**Can the treatment 'miss' its target?**

No. There are many safety measures in place which ensure that the nerve is precisely targeted.

**What do I feel during the treatment?**

The frame, which at this point will still be attached to your head, will be positioned and fixed in the Gamma Knife.

For you, the treatment will be similar to having another scan. You will lie on a couch, listen to music and will feel no pain. Claustrophobic patients may find the confined space difficult but the space is less confined than the MRI scanner. We have an intercom system so it is possible to talk to the radiographers at any time.

**What happens after?**

We will remove the frame, clean the points where it was attached and take you up to the ward. As a result of the frame application and the long day, you may feel tired or even have a headache that afternoon. Local patients may go home that evening but people from further away may need to stay overnight. This may involve an overnight stay in hospital or nearby accommodation dependent on your consultant's wishes and your preferences. In the morning if you are in hospital you will be visited by a member of the team and discharged home.

Your follow-up will be carried out either in Sheffield (if you are a local patient) or by the clinician who referred you to us (if you came from another unit).
The consultants in the radiosurgical unit will continue to advise on the management of your case and we remain interested in your progress. As a centre with over 30 years' experience treating many rare conditions, we regularly carry out clinical audit, service evaluation and research projects. The information we gather in these exercises helps to build on our understanding of radiosurgery and allow us to better inform both you and future patients and may improve our service and treatment. The use of anonymised data about your treatment and follow-up may be used in these activities. If you wish to opt out of us using your anonymised data in this way, please tell a member of the radiosurgical team when you attend at clinic. They will record this on your records and it will in no way affect the treatment or follow-up that you receive from us.

**Are there any side effects and complications?**

Apart from the effects of the local anaesthetic used for the frame application, there are no immediate side effects. You may have a headache by the end of the long day of the treatment, mainly due to the frame.

The only long term side effect is that in treating the trigeminal nerve we can cause numbness. With a single treatment 30% of patients get some numbness, but if pain recurs and a treatment is repeated this risk increases to 70%. Most patients with numbness are happy as numbness is generally associated with good pain relief. However, occasionally patients can find the numbness intrusive or distressing to the point of regarding it as a problem or painful. These side effects will be discussed with you at your outpatient appointment with your consultant.

**Will I lose my hair?**

No hair is shaved for the treatment and none is lost due to the treatment.
Will I take any tablets?

You will continue your usual medication; please bring your own medication from home with you when you attend. During your stay, but not to take home, you will also receive Dexamethasone, a steroid used to add extra protection to the brain during treatment. This is generally combined with Ranitidine (antacid).

Frequently Asked Questions

Q. Do I need tablets afterwards?
A. You will not need to take home new medication but we would advise you to continue on your pre-treatment medication until there has been significant improvement in your condition.

Q. Will I be radioactive after the treatment?
A. No. When the machine is switched off after your treatment is completed the radiation stops and does not linger in your body.

Q. Can I drive following radiosurgery?
A. You can drive as soon as you feel well enough following radiosurgery. However we do not recommend that you drive yourself home from hospital on the day of treatment.
For further information:

Refer to our web site:

- www.gammaknife.org.uk

Email us at:

- gamma.knife@sth.nhs.uk

You may wish to contact:

- The Trigeminal Neuralgia Association UK
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Please use this space to jot down any questions you may have for the consultant when you come to the clinic.