

UCLH
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Patient Guide to Gamma Knife Radiosurgery for Trigeminal Neuralgia

at The Queen Square Radiosurgery Centre



Gamma Knife Radiosurgery for Trigeminal Neuralgia

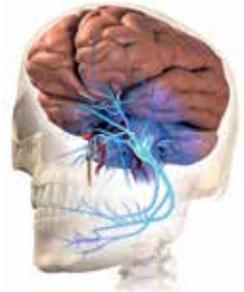
This booklet provides brief information about Gamma Knife radiosurgery for Trigeminal Neuralgia which we hope you will find useful.

Further information is also available on our website and from charities who can provide you with support. Details can be found on page 11. We encourage you to read the information before attending your outpatient appointment enabling you to raise any questions you may have.

What is Trigeminal Neuralgia?

Trigeminal Neuralgia is an extremely severe facial pain that tends to come and go unpredictably in sudden shock-like attacks. It presents as a sudden onset severe shooting or burning facial pain that can occur spontaneously and may last for a few seconds or as consistent short bursts over a number of hours. The pain is normally triggered by light touch, or muscle movement, and can even be stimulated by a gentle breeze on the skin and is described as stabbing, shooting, excruciating or burning. 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. Unfortunately, for most sufferers, the condition is progressive and will worsen over time.



What are the treatment options for Trigeminal Neuralgia?

Medication

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

Surgery

Surgical options for trigeminal neuralgia include microvascular decompression. This procedure involves relocating or removing blood vessels that are in contact with the trigeminal root to stop the nerve from malfunctioning. An incision is made behind the ear on the side of the pain and then, through a small hole in the skull, the surgeon moves any arteries that are in contact with the trigeminal nerve away from the nerve, and places a soft cushion between the nerve and the arteries. If a vein is compressing the nerve, the surgeon may remove it. Surgeons may also cut part of the trigeminal nerve (neurectomy) during this procedure if arteries aren't pressing on the nerve.

Microvascular decompression can successfully eliminate or reduce pain most of the time and most people who have this procedure have no facial numbness afterward.

Percutaneous needle techniques

Under a general anaesthetic a needle is passed through the face, using imaging guidance, into the trigeminal nerve to cause damage using techniques as below. The main shortcoming of this technique is that it causes facial numbness at the same time as giving pain relief. The pain generally recurs, although relief may be achieved for several years.

Glycerol injection. The needle is guided into the trigeminal cistern, a small sac of spinal fluid that surrounds the trigeminal nerve ganglion - where the trigeminal nerve divides into three branches - and part of its root.

A small amount of sterile glycerol, is injected which damages the trigeminal nerve and blocks pain signals. This procedure often relieves pain. However, some people have a later recurrence of pain, and many experience facial numbness or tingling.

Balloon compression. The surgeon threads a thin, flexible tube (catheter) with a balloon on the end through the needle and then inflates the balloon with enough pressure to damage the trigeminal nerve and block pain signals. It successfully controls pain in most people, at least for a period of time. Most people experience at least some transient facial numbness.

Radiofrequency thermal lesioning. This selectively destroys nerve fibres associated with pain detected by sending a mild electrical current through the tip of an electrode and the patient confirming a tingling sensation. The electrode is then heated until it damages the nerve fibres.

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 are not long lasting.

Treatment with Gamma Knife Radiosurgery

The use of Gamma Knife Radiosurgery is a well-established method of treating Trigeminal Neuralgia. This is not a knife in the conventional sense and the treatment does not involve anything being cut.

This procedure uses radiation to damage the trigeminal nerve and reduce or eliminate pain. Relief occurs gradually and may take up to a month and is successful in eliminating pain for the majority

of people. Like the percutaneous ‘ablative’ treatments the pain can return after several years. If pain recurs, the procedure can be repeated or other treatment options considered. This will be discussed further in this information leaflet.

How does the Gamma Knife work?

The Gamma Knife works by focussing beams of gamma radiation and has the ability to treat a defined target area with minimal effect on surrounding tissue. Gamma Knife Radiosurgery is used exclusively for the brain.

Leksell Gamma Knife
Treats brain disorders with a high dose of radiation delivered with surgical precision.

With the treatment planning software, Leksell GammaPlan, the shape and amount of radiation is decided to give an optimal treatment.

The patient can communicate via video camera and an intercom at all times. The treatment time varies between 20 minutes and several hours depending on the complexity of the treatment.

Designed to treat patients with different types of brain disorders, for example benign and malignant tumors.

Radiation unit

- 1 Ionising radiation is emitted whose beams converge on a precise selected area of the brain. The accuracy is about 0.5mm. There is minimal effect on the surrounding healthy tissue.
- 2 A stereotactic frame is attached to the patients head and interlocked to the Gamma Knife unit. This to ensure maximum precision.

Leksell Gamma Knife Perfexion is fully automated. The radiation unit is housed inside of the machine itself. The radiation beams are shaped exactly around the tumor. Several tumors can be treated in one session.

What are the steps before treatment?

If you have been referred for Gamma Knife radiosurgery your case will be reviewed by our specialist multi-disciplinary team (MDT). This includes neurosurgeons, neuro-oncologists, neuroradiologists, medical physicists and radiographers who will determine if Gamma Knife Radiosurgery is a suitable treatment for you.

If suitable you will then be invited to an outpatient appointment with a consultant and to attend a pre-assessment clinic led by radiographers.

You may have had some of your questions answered by your referring Consultant. You may also have had information from other sources (GP, Internet, other patients etc) which may need to be put into context. Indeed you may have had contact with our office and received some answers from our staff.

We must seek your consent for any procedure or treatment beforehand. We will explain the risks, benefits and alternatives where relevant before asking 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.

You will be shown around where treatment will be undertaken and meet with one of the medical staff, who will take your history, check you for general medical problems and determine any specific requirements to ensure that the treatment day goes smoothly.

Some blood tests may be required in preparation for treatment day. We would then plan your admission for treatment.

Things to consider:

Write down two or three of your most important questions

- List or bring all your medicines and pills – including vitamins and supplements.
- Ask for an interpreter or communication support if needed.
- Ask a friend or family member to come with you, if you like.

During your appointment

- Don't be afraid to ask if you don't understand.
- If you don't understand any words, ask for them to be written down and explained.
- Write things down, or ask a family member or friend to take notes.

Before you leave your appointment

Check:

- You've covered everything on your list
- You've understood what will happen next
- You know who to contact with any concerns or questions

Risks of Gamma Knife Radiosurgery

As with every procedure, there are some risks associated with Gamma Knife Radiosurgery. In order to make an informed decision and give your consent, you need to be aware of the possible side effects of this procedure and that you will be exposed to radiation. The consultant will talk to you about the potential risks and side effects of Gamma Knife Radiosurgery for your individual circumstances at your outpatient appointment.

What will happen on treatment day?

You are welcome to have somebody to accompany you all day if this would make you feel more comfortable.

Typically patients are admitted on the morning of treatment, however some, dependent on clinical needs, may be admitted the evening before and this will be discussed with you at your outpatient appointment.

We need to target the area to be treated precisely. To guide us, we use a lightweight metal head frame that allows us to accurately pinpoint the target to be treated in your brain. It also prevents your head from moving during imaging and treatment procedures. For some patients, according to clinical needs the frame may be replaced by a mask¹.

The frame fitting involves a small degree of discomfort, but most patients tolerate it remarkably well. The application of the head frame requires four small injections to administer local anaesthetic (similar to having a dental treatment) in order to numb the sites where the 4 pins are to be used to secure the frame.

The whole procedure takes about 5 - 10 minutes during which you may experience some minor discomfort from the wearing of the head frame but will quickly get used to this. You will have the frame attached until treatment is completed, as all measurements are taken from this reference.

You will then be taken to the MRI scanner to have images taken. Once your scan is complete, you will be taken to the Gamma Knife centre where you can have light refreshments and a rest.

¹If a mask is being used the treatment day remains the same as described but reference to frame fitting/removal is not relevant. Further information on treatment using a mask will be provided at your outpatient appointment.

During your rest time, the medical physicist and a consultant neuroradiologist uses a specially designed computer system to calculate a precise and accurate treatment plan based upon your scans.



This treatment plan is unique to you as every patient's plan is individually designed to address the specific medical condition. Once complete, your Consultant reviews and accepts this plan and prescribes your treatment.

The treatment is similar to having a scan, and you will be lying down with your head frame supported to ensure that you are sufficiently still. During the treatment you will be awake and be able to communicate with the treatment team through an audio and video connection. If necessary, breaks can be introduced into the treatment process to ensure your comfort whilst you are treated.



Following treatment we will remove the frame, clean the points where it was attached and allow you time to recover. You may feel tired or even have a headache that afternoon as a result of the frame application and the long and busy day. Typically you will be discharged home the same day but some patients do stay on a ward and are discharged the next morning. The treatment day remains the same

as described but reference to frame fitting/removal is not relevant. Further information on treatment using a mask will be provided at your outpatient appointment.

We will follow up on your progress working with the consultant who referred you to us. This will be discussed and explained to you following your treatment and your consultant will inform you about when he/she would like to see you again. They will also write to your GP, giving them details of your treatment and after care.

Your questions answered

Q: What do I feel during the treatment?

A: The frame, which at this point will still be attached to your head, will be positioned and fixed within 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.

Q: Are there any side effects and complications?

A: Side effects can vary greatly between individuals. Facial numbness sometimes occurs and can be delayed appearing several months after treatment. Rarely the cornea of the eye can be made insensitive. The consultant will discuss these with you in more detail when you are seen in clinic. From the procedure itself apart from the effects of the local anaesthetic used for the frame application most patients will have no immediate side effects. You may have a headache by the end of the treatment day, mainly due to the frame and some nausea may occur during the first 48 hours. Rarely, some patients may feel tired for a few days or may experience temporary mild discomfort or numbness at the pins fixation sites.

Q: How will I feel after treatment?

A: Radiosurgery does not leave you “radioactive” in any way and you are free to resume contact with children and pregnant women after leaving the treatment room. Over the next few days you may feel tired and you may feel some discomfort in the areas where the frame was fitted. Mild painkillers may be taken if you experience this.

Q: After treatment is there anything I should or shouldn't do?

- Do not scratch the scabs over the pin sites as they act as a barrier to infection and should fall off in a few days. Also, for

the same reason you should refrain from washing your hair for the next 3-4 days

- Do not use any types of creams or lotions on the pin sites
- Do take mild painkiller for headache or soreness
- Do contact your GP if you find the pin sites becoming more painful, red or swollen
- Do contact us if you have any concern or unanswered questions

Q: Will I lose my hair?

A: The treatment does not usually cause any hair loss although local hair loss may occur with superficially located targets. This will usually grow back within 3 months.

Q: When can I resume my normal routine?

A: As soon as you feel well enough. This can be the next day after treatment or you can wait a few days.

Q: When can I go back to work?

A: The same as above applies to returning to work, although most people choose to take a few days rest before going back.

Q: When will it be safe to fly?

A: If you have a holiday booked, there is no reason why you can't fly because of radiosurgery.

Q: Can a mask be used instead of a frame?

A: For only some patients according to clinical needs and suitability. Most treatments continue to be undertaken using the frame

For further information you can:

Refer to our website: www.queenssquaregammaknife.co.uk

Other sources of useful information and support are available from the Trigeminal Neuralgia Association UK (Tel: 01883 370214 Web: <https://www.tna.org.uk/>)

If you have any queries or problems please contact us. Details are on the inside back cover.

Patient feedback

Your complete satisfaction is very important to us and we kindly ask all patients to provide feedback via a questionnaire sent a few days after treatment.

Sometimes, we may not meet your expectations and if there is something we need to improve, please tell us. If we cannot resolve your issue immediately then you can make a formal complaint and a leaflet explaining how is available at the centre and further information is available on our website.

We ensure complaints are investigated fully and learn from them to avoid re-occurrence.

The Queen Square Radiosurgery Centre
The National Hospital for Neurology and Neurosurgery
Queen Square, London WC1N 3BG

Tel: 020 3448 4077
Fax: 020 3448 4078
email: uclh.infogkqs@nhs.net
www.queensquaregammaknife.co.uk

DIRECTIONS:

By Rail: Euston, King's Cross and St Pancras are all only about 15 minutes walk from the hospital.

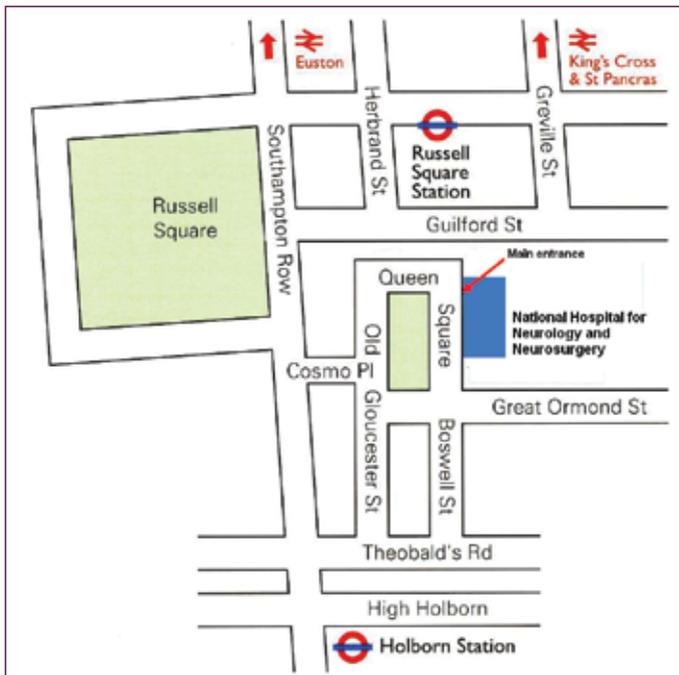
By Bus: Southampton Row - no's 59, 68, 91, 168, 188, 501

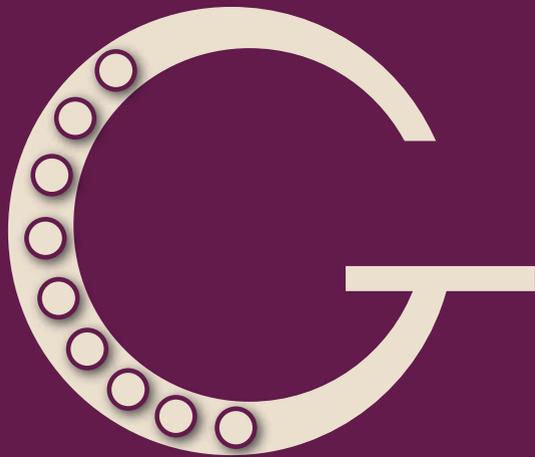
Theobalds Road - no's 19, 38, 55, 243

High Holborn / New Oxford Street - no's 8, 25, 242, 501, 521

By Tube - Nearest tube stations:

Russell Square (Piccadilly Line), Holborn (Central and Piccadilly Lines). Both within walking distance





www.queensquaregammaknife.co.uk