

# Patient Guide to Gamma Knife Radiosurgery for Arteriovenous malformation (AVM)

at The Queen Square Radiosurgery Centre



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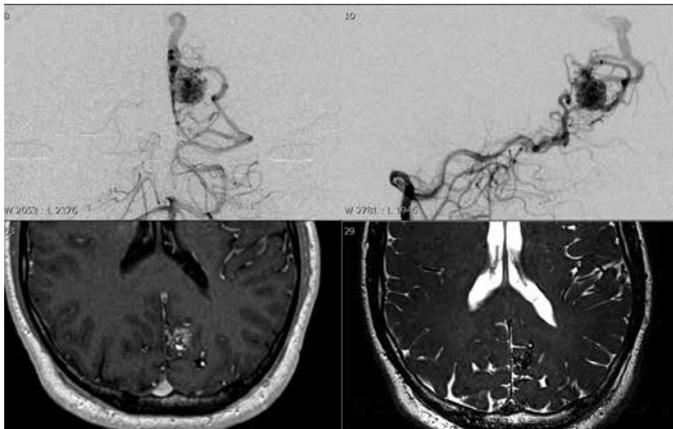
This booklet provides brief information about Gamma Knife radiosurgery for arteriovenous malformation which we hope you will find useful.

Further information is also available on our website and from charities who can provide you with support. Details can be found on page 12. We encourage you to read the information before attending your outpatient appointment enabling you to raise any questions you may have.



# What is an AVM?

An arteriovenous malformation (AVM) is a complex, tangled web of abnormal blood vessels that creates a direct connection (shunt) between arteries and veins. They are congenital (present from birth) and can develop anywhere in your body but occur most often in the brain or spinal cord. The size of brain AVM's can vary largely, from micro AVM's (few millimetres) to very large, measuring more than 6cm in diameter. The most common symptoms of



AVM include haemorrhaging (bleeding), seizures, headaches, and neurological problems such as paralysis or loss of speech, memory, or vision.

By far, the most important risk of a brain AVM is bleeding as they contain abnormal and therefore “weakened” blood vessels that direct blood away from normal brain tissue. These vessels may dilate over time. Eventually they may burst from the high pressure of blood flow, causing bleeding into the brain. They have a 2 to 4% risk of spontaneous haemorrhage each year. Roughly 10% of the haemorrhages will be fatal and about 15% of victims will suffer a continuing neurological deficit, such as weakness, sensory or visual loss, or speech abnormality.

# What are the treatment options for AVM's?

There are several potential treatment options for AVM. The main goal of treatment is to prevent haemorrhage, but treatment to control seizures or other neurological complications also may be considered. Your doctor will determine the most appropriate treatment for your condition, depending on your age, health, and the size and location of the abnormal blood vessels.

## Watch and Wait

You can leave the AVM untreated but this carries a high risk of a brain haemorrhage - 2-4% each year. This risk increases year on year, so for young people the risk of having a haemorrhage in their lifetime may be considerable, even around 80%. If you have a bleed you may recover fully, your brain may lose some of its functions (e.g. paralysis, like a stroke) or you may die.

## Surgery

Under general anaesthetic the AVM is accessed via the skull. With the help of a high-powered microscope, the surgeon seals off the AVM with special clips and carefully removes it from surrounding brain tissue. Resection is usually done for easily accessible AVMs near the surface and in less critical parts of the brain, when the AVM can be removed with little risk of haemorrhage or seizures. AVMs that are in deep brain regions carry a higher risk of complications. Also, it may not be possible to remove it all and then you would be considered for the other options again.

## Embolisation

A long, thin tube (catheter) is inserted by a radiologist into a leg artery and is threaded through blood vessels to the brain using imaging. The catheter is positioned in one of the feeding arteries to the AVM, and an embolising agent inserted, such as small particles, a glue-like substance, microcoils or other materials, to block the artery and reduce blood flow into the AVM. It is less invasive than surgery and maybe performed alone, but is frequently used prior to other surgical treatments to make the procedure safer by reducing the size of the AVM or the likelihood of bleeding.

# Treatment with Gamma Knife Radiosurgery

The use of Gamma Knife Radiosurgery is a well-established method of treating AVM. This is not a knife in the conventional sense and the treatment does not involve anything being cut. It is most appropriate for small compact AVMs, for those that haven't caused a life-threatening haemorrhage and for those where other treatments are not possible or have a high risk of complications because of the location or of the vessels conformation.

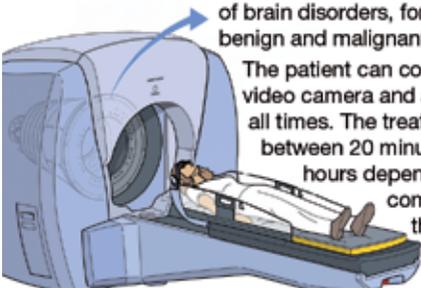
An AVM diameter of 3cm is generally considered to be a cut-off for Gamma Knife treatment, although sometimes larger AVM's can be accepted when no other treatments are possible.

## Leksell Gamma Knife

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

Treats patients with different types of brain disorders, for example benign and malignant tumors.

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.



## Radiation unit

1 Ionising 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 is to ensure maximum precision.

## 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. The radiation starts off a process similar to an inflammation within the vessel wall, which makes the wall thicken inwards, reducing the inner diameter and eventually leads to the closing up of the abnormal vessels. The AVM will not disappear, but it will be converted into something like a scar. This requires a minimum of 3-4 years to be completed only after which the risk of haemorrhage can be ruled out.

# 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) including neurosurgeons, neuro-oncologists, neuroradiologists, medical physicists and radiographers to 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 mask<sup>1</sup>.

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.

***<sup>1</sup>If 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. The rare complications of the radiation treatment are usually delayed and the consultant will discuss these with you in more detail when you are seen in clinic. In the case of large AVM's or for patients with known seizures, there is a higher risk to present one or two seizures in the first 24 hours after treatment. 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:** Will I be able to drive immediately after my treatment?

**A:** For some types of AVM's patients will not be allowed to drive a car or motorcycle for one month. This can be five years to drive a bus or lorry. You must inform the DVLA of your condition and further information can be found at <https://www.gov.uk/arteriovenous-malformation-and-driving>

**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.

# 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.

## **For further information you can:**

Refer to our website: [www.queenssquaregammaknife.co.uk](http://www.queenssquaregammaknife.co.uk)

Other sources of useful information and support are available from AVM Support (<http://www.avmsupport.co.uk/>) and AVM Survivors Network at (<http://www.avmsurvivors.org/>)

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

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](mailto:uclh.infogkqs@nhs.net)  
[www.queensquaregammaknife.co.uk](http://www.queensquaregammaknife.co.uk)

**DIRECTIONS:**

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

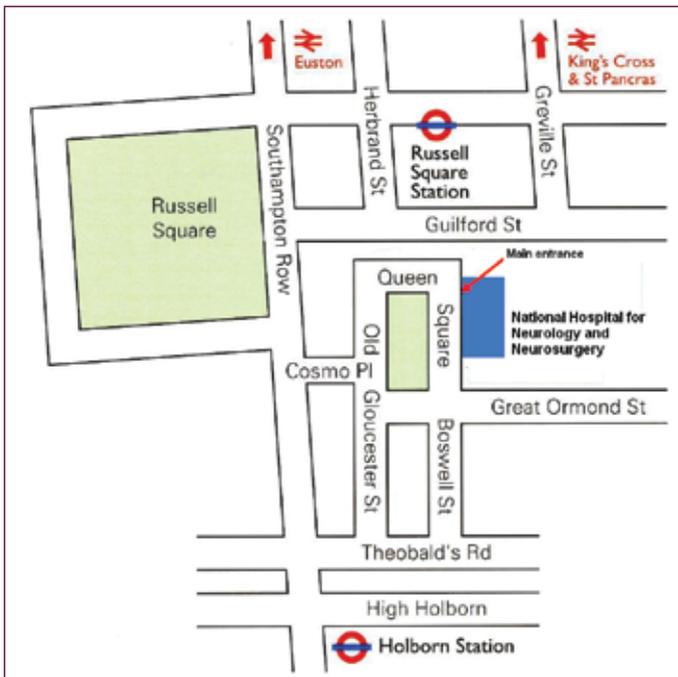
By Bus: Southampton Row - no's 59, 68, 91, 168, 188, 501

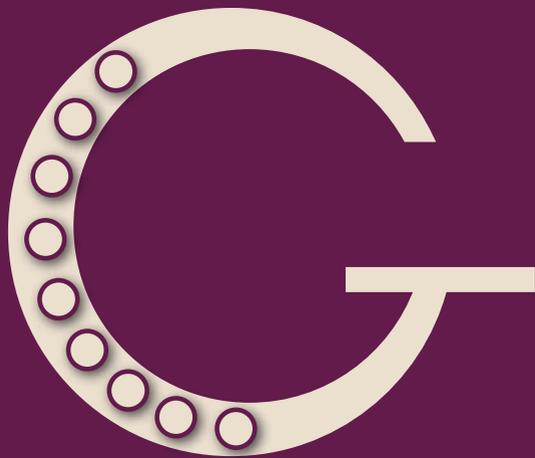
Theobalds Road - no's 19, 38, 55, 243

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](http://www.queensquaregammaknife.co.uk)