

# Vascular malformations of the brain



Brain & Spine  
Foundation

A guide for patients and carers

The Brain & Spine Foundation provides support and information on all aspects of neurological conditions. Our publications are designed as guides for people affected by brain and spine conditions: patients, their families and carers. We aim to reduce uncertainty and anxiety by providing clear, concise, accurate and helpful information, and by answering the common questions that people ask. Any medical information is evidence based and accounts for current best practice guidelines and standards of care.

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# Introduction

This booklet provides information on vascular malformations of the brain. It describes vascular malformations and provides information on common symptoms, tests and investigations and possible treatments. (Please note that it does not include information on brain aneurysms. Please see our booklet, *Subarachnoid haemorrhage*, and fact sheet, *Coiling of brain aneurysms*, for information on brain aneurysms and their treatment.) Sources of further support and information are listed in the [Useful contacts](#) section. References are available on request.

# Common questions

## What are vascular malformations of the brain?

Vascular malformations of the brain are a group of disorders that involve abnormal connections of some of the blood vessels in the head. ('Vascular' refers to blood vessels and 'malformation' means abnormally shaped or formed.)

There are different types of vascular malformation. Each affects a different part of the network of blood vessels.

The main types of vascular malformation of the brain are:

- Arteriovenous malformation (AVM) of the brain
- Arteriovenous fistula (AVF) of the dura (the brain's outer covering)
- Cavernous malformation (cavernoma)
- Developmental venous anomaly
- Capillary telangiectasia

These different types of vascular malformations are explained in the following pages.

Some vascular malformations are difficult to categorise because they share the characteristics of more than one particular type of malformation.

A person with a vascular malformation will usually have just one but it is possible to have more than one.

# Blood vessels

The heart and blood vessels are part of the circulatory system (also known as the cardiovascular system). Blood carrying oxygen and nutrients is pumped from the heart and travels through the body via a network of blood vessels comprising the arteries, capillaries and veins.

**Arteries:** the muscular blood vessels which carry oxygenated blood away from the heart, towards the capillaries and to all parts of the body.

**Veins:** the thin-walled blood vessels which carry deoxygenated blood back to the heart and lungs.

**Capillaries:** the network of fine blood vessels that carry blood between the smallest arteries and the smallest veins throughout the organs and tissues of the body.

## Arteriovenous malformations (AVMs)

### What is an arteriovenous malformation (AVM)?

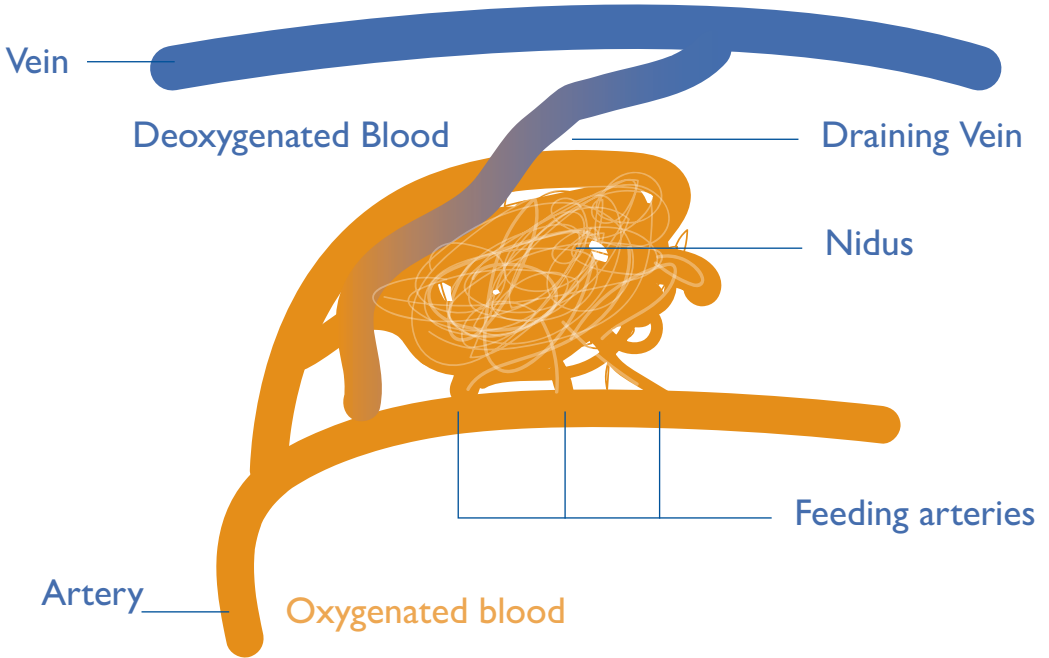
Normally, there is a fine network of capillaries running between the arteries and the veins throughout your brain. An arteriovenous malformation or AVM is the complex tangle of arteries and veins which develops when the capillaries are missing in one area. A more old-fashioned name for an AVM is an ‘angioma’.

Occasionally, only a single artery and vein are involved, forming a particular type of AVM called an **arteriovenous fistula** or **AVF** (a fistula is the medical name for an abnormal tunnel or connection).

Usually, capillaries slow down blood flow. In AVMs and AVFs where there are no capillaries, blood flows at high pressure from muscular arteries directly into thin-walled veins. This abnormal flow of blood is known as a **shunt**.

AVMs and AVFs range in size from just a few millimetres to several centimetres across. They can occur in any part of the brain and spinal cord. They can also develop within the brain’s outer covering, the dura mater or **dura**. An example of an AVF of the dura is a carotid-cavernous fistula (CCF). This is an abnormal connection between the main artery supplying the brain (the carotid artery) and one of the draining veins behind the eyes which can cause swelling and redness in one eye.

## Arteriovenous malformation



**Nidus:** the knotted tangle of blood vessels in an AVM.

**Shunt:** the direct flow of blood from an artery to a vein.

**Dura:** the membrane or layer which forms the outer covering of the brain; the dura mater.

**Arteriovenous fistula (AVF):** an abnormal connection between an artery and a vein. It allows blood to flow directly from the artery to the vein without passing through any capillaries.



## What causes AVMs?

We do not know the cause of AVMs in the brain but we do know that they are not cancerous (they are not linked to brain tumours) and they are not infectious.

We think AVMs are due to a problem with the normal growth of capillaries during early development in the womb. However, although an AVM might have been present before birth, it usually takes some time for it to produce any symptoms.

Very rarely, AVMs can run in the same family with an identifiable genetic cause. They are only inherited in a condition called **hereditary haemorrhagic telangiectasia (HHT)** in which AVMs can also occur in the lungs. People with this condition might experience nosebleeds, red spots on their skin and bleeding from their stomach lining and intestines. It is also known as Osler-Weber-Rendu disease.

Dural AVFs can be caused by head injuries, brain surgery, infections of the brain or blood clots in the large veins that drain the brain. Sometimes there is no obvious cause.

## Cavernous malformations (cavernomas)

### What is a cavernous malformation?

Cavernous malformations can also be known as cerebral cavernous malformations (CCMs), cavernomas, cavernous angiomas and cavernous haemangiomas.

A cavernous malformation is a cluster of abnormal, enlarged small blood vessels. It looks like a raspberry. The walls of the blood vessels in a cavernous malformation are thinner than usual, less elastic and prone to leaking. This can cause bleeding in the brain (haemorrhage). Depending on how big the bleed is and where it occurs, this may cause a person to experience neurological symptoms ([see information on stroke on page 14](#)).

Cavernous malformations vary in size from just a millimetre to several centimetres across. They can be found anywhere within the brain. Sometimes, they are associated with a nearby developmental venous anomaly ([see page 10](#)).

Many people with cavernous malformations will never experience any symptoms (asymptomatic). It has been estimated that one in every 600 people in the UK may have an asymptomatic cavernous malformation. If symptoms do develop, this will usually be earlier in life and normally by the time a person reaches their 30s.

Cavernous malformations might get bigger but they are not cancerous (they are not linked to brain tumours) and they are not infectious.

## What causes cavernous malformations?

In most cases, people have just one cavernous malformation and no family history of them. It is not known why cavernous malformations occur in these people.

For at least 20% of people affected by cavernous malformations there is a genetic cause. This means that different generations of the same family share a faulty gene responsible for the formation of cavernous malformations. Scientists have identified three genes that can cause cavernous malformations (known as CCM1, CCM2 and CCM3). A mutation on any of these genes can cause cavernous malformations to form. In families where cavernous malformations are genetic, the people affected often have several of these abnormalities. The genetic form is usually discovered in people when they are younger, as multiple abnormalities are more likely to cause symptoms.

It is also known that some people can develop cavernous malformations after receiving radiation treatment involving the brain.

## Developmental venous anomalies (venous malformations)

### What is a developmental venous anomaly?

A developmental venous anomaly is an abnormal dilated (widened) vein, a cluster of dilated veins, or a vein that takes an unusual course.

Developmental venous anomalies are also sometimes known as venous malformations or venous angiomas.

### What causes developmental venous anomalies?

We do not know what causes developmental venous anomalies or exactly how common they are. It is thought they are congenital (meaning a person is born with them). They rarely seem to cause any problems for the people who have them.

Developmental venous anomalies are sometimes associated with a nearby cavernous malformation which might be the cause of any symptoms.

## Capillary telangiectasia

### What are capillary telangiectasia?

Capillary telangiectasia are clusters of abnormally swollen small blood vessels (capillaries). They are usually no bigger than two to three centimetres wide and are usually harmless.

Most people don't experience any symptoms. However, if a person develops large numbers of capillary telangiectasia, this can lead to symptoms such as headaches and seizures. Capillary telangiectasia are unlikely to change over time or suddenly burst and bleed out (rupture). For this reason they rarely require treatment.

### What causes capillary telangiectasia?

It is not known exactly what causes capillary telangiectasia. It is thought that they could be associated with other vascular malformations.

### Moyamoya disease

People with moyamoya disease have blocked arteries at the base of the brain which restricts the brain's supply of blood. The condition was first discovered in Japan and moyamoya means 'puff of smoke' in Japanese. The name describes the appearance of the very small, abnormal blood vessels that form to compensate for the blocked arteries.

It is a rare condition and tends to affect children more than adults. The exact cause is unknown but it can run in families so there is a possible hereditary risk. The main symptoms are recurring strokes or TIAs (transient ischaemic attacks). The main treatment is surgery to improve the flow of blood in the affected area.

(You might like to read our fact sheets, *Stroke* and *TIA*, for further information.)

### Could I have prevented my vascular malformation?

No. We have not established clear risk factors for vascular malformations of the brain in the way that, for instance, smoking has been established as a risk factor for lung cancer.

### Are there warning signs?

No. Most people experience no warning signs before the onset of their symptoms and many people do not experience any symptoms.

### Are my family at risk?

There is no known risk of inheriting AVMs, apart from the condition hereditary haemorrhagic telangiectasia (HHT) (see page 7).

Cavernous malformations can be genetic. This is very unlikely to be the cause if you only have one cavernous malformation. Three genes are known to be responsible for inherited cavernous malformations (see page 9).

### How common are vascular malformations of the brain?

AVMs and cavernous malformations are uncommon and affect less than 1% of the population.

Apart from the genetic form of cavernous malformations, which is more common in the Hispanic community of New Mexico, vascular malformations do not appear to be more common in certain countries or races. Men and women are affected equally.

## What are the symptoms of vascular malformations of the brain?

The symptoms you might experience depend on the type of vascular malformation you have, its size and where it is located in your head. Most of the time, vascular malformations cause no symptoms at all.

The tests and investigations you have might show up other factors which could affect your risk of experiencing any of the symptoms associated with vascular malformations. For example, their exact location and the routes veins take from them.

### Strokes

Strokes affecting people with vascular malformations are usually due to bleeding in the brain (a haemorrhage). The bleeding occurs through the thin blood vessel walls of the vascular malformation. The symptoms of a stroke usually appear suddenly and might be accompanied by nausea (feeling sick), vomiting (being sick) and loss of consciousness.

#### Main symptoms of stroke

- Headache
- Physical problems in one side of the body (numbness, weakness)
- Drooping on one side of the face
- Speech problems (slurred speech, muddled words)
- Visual problems (blurred vision, loss of vision)
- Balance problems
- Confusion

Bleeding in the brain is the most serious complication of a vascular malformation because of the risk of damage to the brain. It is treated as a medical emergency. Sometimes a bleed from a vascular malformation might be so small it causes no symptoms.

The key test for stroke is a CT scan or MRI scan (see [Tests and investigations section](#)). Some people might experience stroke-like symptoms despite their brain scans showing no signs of bleeding. This might be due to pressure changes in the blood vessels. These stroke-like symptoms might disappear, persist or gradually get worse over time.

(You might like to read our fact sheet, [Stroke](#), for further information.)

Please note that because further research on the subject is needed, the following figures for the risk of bleeding from vascular malformations are estimates:

- The risk of bleeding from an AVM of the brain for the first time is approximately 1% in any given year. In other words, for every 100 people with an AVM that has never bled, 99 will not have a bleed in the next year and one will.
- If someone has had a bleed from an AVM and received no treatment, the risk of a subsequent bleed is roughly 5% per year. In other words, for every 100 people with an AVM that has bled but not been treated, 95 will not have a bleed in the next year and five will. This risk may vary according to the exact location of the AVM and the way the veins drain from it.



- The annual risk of bleeding from cavernous malformations varies according to their location and whether they have caused a bleed before:
  - Cavernous malformation outside the brainstem with no previous bleed: 0.8% per year
  - Cavernous malformation in the brainstem with no previous bleed: 1.6% per year
  - Cavernous malformation outside the brainstem with a previous bleed: 3.7% per year
  - Cavernous malformation in the brainstem with a previous bleed: 6.2% per year
- The risk of bleeding from dural AVFs is not well known.
- The risk of bleeding from developmental venous anomalies is very low and certainly much less than 1% per year.

In pregnancy and during labour, the risk of bleeding may be higher for AVMs (although studies have been inconsistent about this). The risk does not seem to be raised for cavernous malformations, and nothing is known about whether the risk of bleeding from other types of vascular malformation is affected.

## Epilepsy

For people with an AVM or cavernous malformation of the brain, in any given year there is a 1 in 100 (1%) risk of developing epilepsy for the first time.

Epileptic seizures can be caused by a vascular malformation pressing on the brain and causing excessive electrical activity. This electrical activity causes the part of the brain near the vascular malformation to become overactive, resulting in a seizure. There are many different types of seizure and each person's experience will differ. Vascular malformations in certain parts of the brain (the brainstem and the cerebellum) do not cause seizures.

You might experience unusual feelings and uncontrollable muscle movements in the parts of your body controlled by the affected part of your brain. This is called a partial (or focal) seizure.

You might experience longer seizures that affect the whole of your body with convulsions (jerking or shaking movements). This is called a generalised seizure. You might lose consciousness during a generalised seizure.

You might be prescribed anti-epilepsy drugs to try to control your seizures. There are many different types of anti-epilepsy drugs and the type you are prescribed will depend on your individual situation. You might need to take more than one type. Seizures can often be successfully controlled by these drugs.

(You might like to read out fact sheet, *Epilepsy*, for further information.)

## Headache

Headaches are a common problem for a large number of people and it is sometimes difficult to establish whether they are related to a vascular malformation or have a different cause.



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People with vascular malformations can have headaches that are similar to migraines and might respond to migraine treatments. The pain can be located at the site of the vascular malformation but it is often felt in a different part of the head.

People with dural AVFs can get different types of headache caused by their AVF irritating the pain fibres in the dural membrane.

If drowsiness, unconsciousness or any stroke-like symptoms ([see page 13](#)) accompany a headache you should seek medical attention because of the possibility of a brain haemorrhage.

(You might like to read our booklet, *Headache*, and our fact sheet, *Migraine*, for further information.)

## Visual problems

Visual problems such as blurred vision, double vision or a loss of vision, particularly affecting one eye, can be a symptom of stroke.

Carotid-cavernous fistulas (CCFs) can cause swelling or redness in an eye and the eye might also protrude from its socket more than usual.

## Noises in the head

An AVF of the dura can cause a noise in your head due to the blood flowing through it. The noise is called a bruit. A doctor can hear it using a stethoscope. Occasionally, you might be able to hear the noise yourself. Some people hear it as a distinctive type of ringing or whooshing sound that beats in time with their pulse. This is called pulsatile tinnitus.

## Memory problems

If you have had a brain haemorrhage, you might be left with damage to your brain which can cause problems with your short-term memory, attention and concentration.



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Even without having had a haemorrhage, people with AVMs sometimes report having problems with their memory. This is possibly due to changes in the flow of blood through their brain.

## Anxiety and depression

Although there is no evidence that vascular malformations of the brain directly cause psychological changes, it is quite common for people with this diagnosis to experience anxiety and depression. People often find it difficult to express how they feel or talk about their emotions but it often helps if you can talk to a friend or relative about how you are feeling rather than keep it bottled up inside. Your doctor or clinical nurse specialist might be able to help. You might like to consult the organisations listed in the [Useful contacts](#) section.

## Other symptoms

Other symptoms of vascular malformations of the brain might include speech problems, weakness in the arms or legs, balance problems and enlarged blood vessels on the scalp.

# Tests and investigations

## CT scan

A CT scan (computerised tomography scan) is a special type of X-ray that takes pictures of your brain from different angles.

During the scan you will be asked to lie on a scanner table while the scanner rotates around your head. It is a painless examination and usually takes 5-15 minutes.

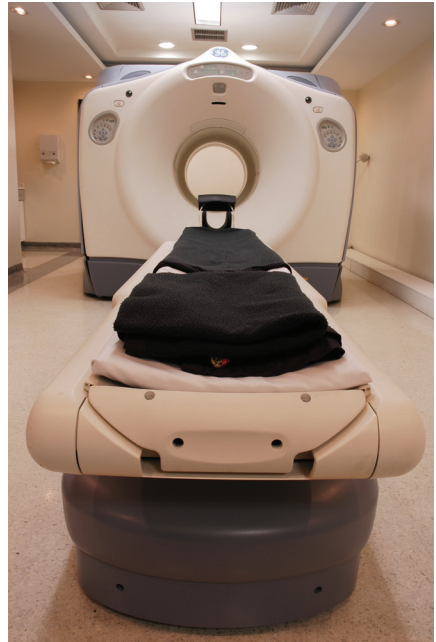
A CT scan might be the first test used to diagnose a vascular malformation. Often, an MRI scan (see below) and/or an angiogram (see page 20) is also required to be sure. You might also have a CT scan after you have a confirmed diagnosis of a vascular malformation to investigate any suspected bleeding in your brain.

Your CT examination might include a CT angiography (CTA). It is quicker and less invasive than an angiogram. A special dye (called contrast agent) is injected into a vein in your arm and flows around your blood stream to highlight the blood vessels in your brain.

## MRI scan

An MRI scan (magnetic resonance imaging scan) uses strong magnetic fields and radio waves to produce very detailed pictures of the head and brain. You might have an MRI scan after, or instead of, a CT scan.

During the scan you will lie flat on a bed that slowly moves into a long tube. The scan is painless but the scanner is very noisy. Earplugs



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or headphones are provided. Some people find the confined space in the scanner tunnel claustrophobic. If you think you will feel anxious or uncomfortable in the confined space of the scanner tunnel, or experience claustrophobia, you should tell the staff before the scan. You should also tell them if you unexpectedly feel anxious just before you are due to enter the scanner tunnel. During the scan, the radiographer who controls the scanner will be in another room but you will be able to talk to them through an intercom.

An MRI scan usually provides more detailed information about brain AVMs than a CT scan. It is the most accurate test for diagnosing cavernous malformation and can be used to confirm whether someone has just one or several of these vascular abnormalities.

Your MRI examination might include a magnetic resonance angiography (MRA) which produces detailed images of the blood vessels. It is quicker and less invasive than an angiogram (see below). A special dye (called contrast agent) is injected into a vein in your arm and flows around your blood stream to highlight the blood vessels in your brain.

(You might like to read our fact sheet, [Brain and spine scans](#), for further information on CT and MRI scans.)

### Angiogram

An angiogram is an X-ray test to produce pictures of blood vessels. Unlike the CT or MRI scans, it requires some preparation and sometimes also a short stay in hospital. The doctors looking after you will carry out some blood tests beforehand. An interventional radiologist will explain the risks and benefits of the procedure and you will be asked to sign a consent form.

The radiologist will give you an injection of local anaesthetic to numb your groin so you will not be able to feel what is going on. The radiologist will then put a very small tube, called a 'catheter', into the main blood vessel in your groin (the femoral artery). The catheter is

guided through other blood vessels in your body until it reaches the blood vessels in your neck that supply the brain. You will not feel it moving inside you.

When the catheter is in the right position, the radiologist will inject a special dye through it (called contrast agent), and some X-ray images will be taken. Blood vessels don't normally show up on X-rays, but this dye makes them visible.

The radiologist will reposition the catheter in different blood vessels in the neck, and take more sets of X-rays with further injections of dye. The injections may give you a general warm feeling, but this goes away quickly.

It is very important that you remain still throughout the procedure to ensure the pictures taken are as clear as possible. You might be asked to hold your breath or avoid swallowing for short periods of time.

The test is likely to take between 20 minutes and an hour. Afterwards, pressure will be applied to the point at which the catheter was inserted to seal it and stop any bleeding.

An angiogram is usually the most accurate test for vascular malformations of the brain, although it does not show cavernous malformations. After you have a confirmed diagnosis, to help plan your treatment you might need a more detailed angiogram using finer catheters to show the precise structure of an AVM of the brain or an AVF of the dura.

(You might like to read our fact sheet, [Angiogram](#), for further information.)

## Possible treatments

It is not a simple decision whether to go ahead with any of the possible treatments for vascular malformations of the brain. The risks of leaving your vascular malformation alone need to be weighed up against the risks and benefits of treatment. Your own preferences will also be taken into account. If you attend a specialist clinic, a team of doctors might be involved in making this decision with you.

The aim of treatment is to protect you from experiencing or developing any future problems related to your vascular malformation by getting rid of it completely. There is no treatment that can undo any damage that has already been done to the brain.

The main methods of treatment are **craniotomy**, **stereotactic radiosurgery** and **embolisation**. You might have a one-off treatment, a combination of more than one treatment or – as with embolisation – several separate treatments. The most appropriate treatment will depend on the type of vascular malformation, its location in the brain as well as a patient's age and health.

Sometimes, the best option for an individual is to have no treatment at all. Randomised controlled trials are the fairest way to test treatments and to work out whether or not it is better to have treatment. One such trial was the ARUBA trial (A Randomised trial of Unruptured Brain Arteriovenous malformations). The trial was stopped early, however the data collected demonstrated that for patients with brain AVMs that had never bled the risk of stroke was three times higher if they were treated than if they were not treated. This data was collected over approximately three years of follow-ups with patients and it is important to note that the balance of risks and benefits is unclear in the long run.

There is a need for more research into the treatment of all types of vascular malformations of the brain.



## Craniotomy

A craniotomy is an operation to open the head in order to expose the brain. The word craniotomy means making a hole (-tomy) in the skull (cranium). The operation is carried out by a neurosurgeon who specialises in surgery of the brain and spine.

Craniotomy can be used to treat AVMs of the brain, and sometimes AVFs of the dura, by detaching the AVM from the arteries that supply it with blood and the veins that drain it. Craniotomy is also used to remove cavernous malformations. Craniotomy is the most invasive treatment option, but the most likely to get rid of the vascular malformation completely.

The decision to go ahead with a craniotomy will be based on the particular risks associated with your condition and how safe it is to operate on your vascular malformation, depending on its size and exact location. Your doctor will discuss the procedure with you, including the potential benefits and risks.

### What happens before a craniotomy?

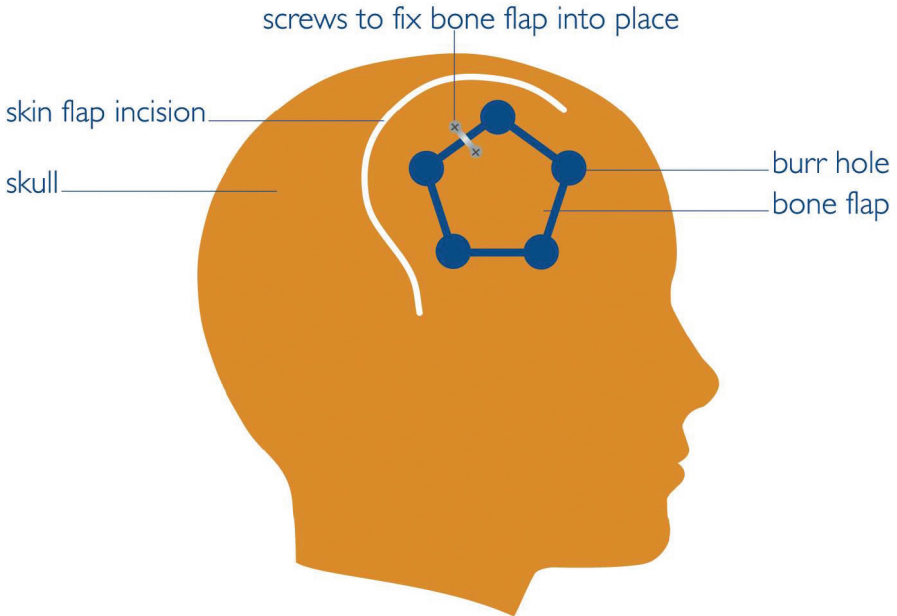
You will be admitted to hospital the day before your surgery is scheduled. You will undergo a thorough examination and tests to make sure you are fit for the surgery. You should not eat for six hours or drink for two hours before the operation. An anaesthetist will give you a general anaesthetic so you will be asleep before you are taken into the operating theatre.

### What happens during a craniotomy?

An area of your head is shaved over the point at which the vascular malformation can be reached. An incision (cut) is made in the scalp, a skin flap is peeled back, burr holes are drilled in the skull and a piece of bone ('bone flap') is cut out to reveal the brain and vascular malformation underneath. The vascular malformation will then be carefully detached from the surrounding blood vessels and brain tissue. This can take several hours.

The bone flap is then replaced and the scalp is stitched back together. The bone flap is usually fixed into place with small metal screws to prevent movement and encourage better healing.

### Craniotomy incision and replacement of the bone flap



### What happens after a craniotomy?

After surgery, you will be taken to a recovery area, usually in the intensive care unit, where you will be closely monitored. When your condition has stabilised, you will be transferred back to the ward.

If you have headaches or feel nauseated (sick), you will be given medication to help manage these symptoms. You may be given steroids to prevent swelling and anti-epileptic drugs to prevent seizures (fits). You should be able to eat, drink and move as soon as you feel able. You will be discharged as soon as your condition is stable.

Some weeks or months after the operation, your doctors will want to repeat an angiogram or MRI scan to see how effective the surgery has been. You will need to convalesce at home for a few weeks and some people require physiotherapy in a rehabilitation unit. It is likely that you will need to take several weeks off work after the operation. Some people need to take several months off.

As with any treatment, there are potential risks and benefits with a craniotomy. It might be possible to remove your vascular malformation completely and this could protect you from developing other associated problems in the future. Surgery is sometimes used to remove larger vascular malformations that are too big for either radiosurgery or embolisation to be effective. However, surgery requires a general anaesthetic which has its own risks. Surgery to remove a vascular malformation also carries a risk of stroke as a result of the procedure.

(You might like to read our fact sheet, *Craniotomy*, for further information.)

## Stereotactic radiosurgery

Stereotactic radiosurgery uses radiation to treat small vascular malformations, mainly AVMs smaller than three centimetres wide. Currently, there is insufficient evidence that it can be used to treat cavernous malformations. Despite its name, the treatment is not a surgical procedure and does not involve any incisions (cuts). It works by targeting a high dose of radiation at the vascular malformation in order to cause the affected blood vessels to close up. The treatment is delivered by a machine called a linear accelerator (LINAC) or gamma knife.

## What happens before radiosurgery?

A team of health professionals from several different departments in the hospital will look after you. The main people involved will be a radiotherapist, a neuroradiologist, a radiographer, a physicist, and possibly a neurologist or neurosurgeon.

Careful planning is needed to aim the narrow radiation beams precisely. It is also important that your head stays very still during the treatment. You will be measured and fitted for either a special head frame or mask (depending on the hospital doing your treatment). It will support your head and neck during the treatment. You may need to have some scans before and after to help staff fit your frame/mask and plan your radiosurgery treatment.

### What happens during radiosurgery?

When you arrive for your treatment, your customised head frame or mask will be fitted. If you are being fitted with a head frame, four places on your head will be numbed and pins will be inserted to hold the frame in place.

You might also need to have some more scans, possibly including CT, MRI and angiogram, before the treatment begins. These will provide detailed computer images of your brain which the treatment team will use to decide how to direct the radiation beams accurately. This can take a few hours.

The radiographers will then set up the positions of the table for you to lie on and the radiation machine.

During the actual procedure you will usually be awake; however, you may be given a mild sedative to relax you.

If you are having gamma knife treatment you will lie on a table that slides into the machine, and your head frame/mask will be attached to the table frame. The table moves within the machine.

If you are having LINAC treatment, part of the machine moves around you in order to deliver the radiation beams from different angles.

The radiosurgery might last up to one hour. You will not feel any discomfort during the treatment but you will hear some noise from the machine.

## Embolisation

Embolisation is a way of blocking abnormal blood vessels. It is used to treat AVMs of the brain and AVFs of the dura. The procedure involves injecting liquid glue, or sometimes inserting small metal coils, into the AVM using a long catheter similar to the one used for an angiogram.

Embolisation may block off the blood supply to an AVM and get rid of it completely or it may reduce the size of the AVM. Sometimes, it can reduce symptoms such as noise in the head or headaches.

In some circumstances, embolisation is used to shrink an AVM so that it is suitable for radiosurgery or neurosurgery. It can also be used to reduce the risk of bleeding from the AVM during subsequent neurosurgery.

### What happens before embolisation?

Unless embolisation is performed as an emergency, you will be admitted to hospital the night before or on the morning of the procedure so that routine blood tests can be carried out and you can be prepared for the procedure. You will not be allowed to eat from midnight before the embolisation. The neuroradiologists will discuss the procedure with you, explaining the risks and benefits, and you will be asked to sign a consent form.

On the day of the procedure, you will be taken to the radiology department. You will be given a general anaesthetic.

### What happens during embolisation?

The length of the procedure depends on the complexity of the tangle of blood vessels. Usually, it is a matter of hours. The neuroradiologists thread the catheter from your groin through the blood vessels up to a safe position close to the AVM. They then inject liquid glue or small metal coils through the needle to create an artificial blood clot in the AVM. This blocks the flow of blood through the AVM.

## What happens after embolisation?

You will need to remain flat in bed to prevent bleeding at the point where the catheter entered the blood vessel in your groin.

You will be observed closely by the medical and nursing team looking after you. Many people experience a headache for a short while after the treatment. There are some risks associated with embolisation, so you should report any unusual feelings or sensations that you experience. Normally, people go home within 48 hours of the procedure.

Some weeks or months after the embolisation, your doctors will want to repeat an angiogram to see how effective your treatment has been. If your AVM is large you might need to return for further embolisation treatment over the following weeks or months. If your AVM is not completely sealed, it still carries a risk of further bleeding. In this case, your doctors might decide to try one of the other possible treatments, if they are appropriate, in an attempt to get rid of the AVM.

Embolisation can be used to treat AVMs deep in your brain in areas that would be too difficult to reach during a craniotomy (see page 23). However, it is less likely to seal off an AVM completely in just one go and you might need several separate sessions of treatment.

# Other treatments

## Drug treatment

You may be given medication to manage the symptoms you are experiencing. This might include steroids to reduce swelling in the brain around the vascular malformation before or very shortly after embolisation or a craniotomy. If you experience seizures, you might be given anti-epilepsy drugs (AEDs). Your doctors might recommend you avoid taking aspirin, or other drugs that thin your blood and prevent it from clotting, in case your vascular malformation bleeds.

## Rehabilitation

Your recovery from symptoms caused by your vascular malformation might be gradual. Rehabilitation could help improve your recovery. If you are admitted to hospital, nurses will be available to help you with your everyday needs. If you are staying in hospital or at home, your doctors can refer you for physiotherapy, speech and language therapy or occupational therapy, as appropriate.

It can be difficult to come to terms with having a vascular malformation. You might feel worried, anxious or depressed about your condition. If you are feeling stressed or concerned, you might want to talk to your GP about seeing a clinical psychologist or a counsellor.

**Physiotherapy:** helps physical recovery and the recovery of movements (for example, walking).

**Speech and language therapy:** helps the recovery of communication skills.

**Occupational therapy:** helps redevelop the skills you need to perform everyday activities (for example, washing, cooking and using equipment around the home).

## Everyday activities

Having a vascular malformation does not necessarily restrict your everyday activities. What you are able to do depends on how you are affected, whether you have any treatment and, most importantly, what you feel able to do. If you have any concerns or questions, you should discuss them with your doctor.

### Can I drive?

If you hold a driving licence, you should ask your doctor for advice on your fitness to continue driving. You might need to stop driving if you have epilepsy or have had a brain haemorrhage. You might also need to stop driving after having some types of treatment. You can contact the Driving and Vehicle Licensing Agency (DVLA) for advice and information on medical rules for drivers (see [Useful contacts section for the DVLA's contact details](#)). If there is any doubt about your fitness to drive you can be referred to a special driving centre to be assessed.



If your doctor tells you that you should stop driving, you need to inform the DVLA. This is a legal obligation. If you do not inform the DVLA, or continue driving after you have been told to stop, you could be putting yourself and other people at risk and you will not be covered by your insurance company in the event of an accident.



## Can I fly?

Yes. There are no particular restrictions on flying but you should speak with your doctor if you have any questions or concerns. You should also inform your travel insurance company about your vascular malformation.

## Can I play sport?

Yes. You can resume most sports and exercise once you have recovered from your treatment. You might be advised to avoid contact sports like rugby, boxing or martial arts. You should also be careful if you have epileptic seizures. You can discuss with your doctor any concerns you might have about sports and exercise. As a general rule, you should go ahead if you feel able.

## Can I swim?

Yes. You can swim once any wounds from your treatment have healed. If you have epilepsy you should swim with a companion and let the lifeguard know about your condition.



## Can I have sex?

Yes. You can have sex as soon as you feel ready.

## Can I drink alcohol?

Yes, but it is best to drink in moderation only. There is also a risk of provoking a seizure if you drink too much. If you are taking any medication, you should check with your doctor whether it is safe for you to drink alcohol.

## When can I go back to work?

The timing of your return to work will depend on what sort of work you do. For example, you might need to wait for the renewal of your driving licence. If you experience seizures you should not work at heights or with dangerous machinery.

The general advice is to use your common sense and only return to work when you feel able. You might find it helpful to discuss this with your GP. Some people return to work on a part-time basis before returning full-time.

# Research

Vascular malformations of the brain are rare conditions and our understanding of them is incomplete. They are an important subject for medical research.

In 2015, a report published by the James Lind Alliance identified the top 10 priorities for future research into cavernous malformations. The report was compiled through consultation with patients, their families and carers, health care professionals and researchers working in the field. You can read the report on the Cavernoma Alliance UK website: [www.cavernoma.org.uk/psp/](http://www.cavernoma.org.uk/psp/)



During the course of your treatment, you might be invited to take part in a research study to compare different types of treatment. If you are approached about any studies, they should be fully explained to you and have the approval of the appropriate ethics committee. You are not obliged to take part and can refuse to if you wish.

(You might like to read our fact sheet, *Clinical trials*, for further information.)

# Health professionals

**Neurosurgeon:** a specialist doctor who performs brain and spine operations.

**Neurologist:** a doctor who specialises in the diagnosis and treatment of people with neurological conditions.

**Interventional radiologist:** a specialist doctor who performs procedures such as angiograms and embolisation.

**Neuroradiologist:** a specialist doctor who performs, reads and reports on scans such as angiograms, CT scans and MRI scans.

**Radiographer:** a specialist trained to control the equipment used for scans such as angiograms, CT scans and MRI scans.

**Radiotherapist:** a doctor specially trained to use radiation for the treatment of cancer and other conditions such as vascular malformations of the brain.

**Physicist:** a scientist with specialist knowledge on the use of stereotactic machinery and radiation treatment.

**Clinical nurse specialist:** a nurse who specialises in a particular condition or conditions, for example, vascular conditions in the brain.

**Neurophysiotherapist:** a physiotherapist who specialises in treating people with neurological conditions. A neurophysiotherapist assesses symptoms, plans treatment and treats people with physical problems.

**Speech and language therapist:** a specialist health professional who assesses symptoms, plans treatment and treats people with communication and swallowing problems.

# Useful contacts

## Vascular malformations of the brain:

### **Brain & Spine Helpline**

Brain & Spine Foundation

LG01 Lincoln House

Kennington Park

1-3 Brixton Road

London SW9 6DE

Helpline: 0808 808 1000

[helpline@brainandspine.org.uk](mailto:helpline@brainandspine.org.uk)

[www.brainandspine.org.uk](http://www.brainandspine.org.uk)

*Run by neuroscience nurses, providing support and information on all aspects of neurological conditions for patients, their families and carers and health professionals.*

### **BASIC (Brain And Spinal Injury Centre)**

554 Eccles New Road

Salford M5 5AP

Helpline: 0870 750 0000

[enquiries@basiccharity.org.uk](mailto:enquiries@basiccharity.org.uk)

[www.basiccharity.org.uk](http://www.basiccharity.org.uk)

*Support and information on neurological conditions.*

### **The Brain Charity**

Norton Street

Liverpool L3 8LR

Tel: 0151 298 2999

[info@thebraincharity.org.uk](mailto:info@thebraincharity.org.uk)

[www.neurosupport.org.uk](http://www.neurosupport.org.uk)

*Support and information on neurological conditions.*

### **Cavernoma Alliance UK**

Suites 4 & 5, Somerleigh Gate

Somerleigh Road

Dorchester

Dorset DT1 1TL

Helpline: 01305 213876

[info@cavernoma.org.uk](mailto:info@cavernoma.org.uk)

[www.cavernoma.org.uk](http://www.cavernoma.org.uk)

*Information and support for those living with a cavernoma.*

## **Epilepsy:**

### **Epilepsy Action**

New Anstey House

Gate Way Drive

Yeadon

Leeds LS19 7XY

Helpline: 0808 800 5050

[helpline@epilepsy.org.uk](mailto:helpline@epilepsy.org.uk)

[www.epilepsy.org.uk](http://www.epilepsy.org.uk)

*Support and information on epilepsy.*

### **Epilepsy Society**

Chesham Lane

Chalfont St Peter

Buckinghamshire SL9 0RJ

Helpline: 01494 601 400

[fromthehelpline@epilepsysociety.org.uk](mailto:fromthehelpline@epilepsysociety.org.uk)

[www.epilepsysociety.org.uk](http://www.epilepsysociety.org.uk)

*Support and information on epilepsy.*

## Stroke:

### Stroke Association

Stroke Information Service

Life After Stroke Centre

Church Lane

Bromsgrove

Worcestershire B61 8RA

Helpline: 0303 303 3100

[info@stroke.org.uk](mailto:info@stroke.org.uk)

[www.stroke.org.uk](http://www.stroke.org.uk)

*Support and information on stroke.*

### Different Strokes

9 Canon Harnett Court

Wolverton Mill

Milton Keynes MK12 5NF

Helpline: 01908 317618

[info@differentstrokes.co.uk](mailto:info@differentstrokes.co.uk)

[www.differentstrokes.co.uk](http://www.differentstrokes.co.uk)

*Support for younger stroke survivors, their families and friends.*

## Driving:

### **DVLA (Driver Vehicle and Licensing Agency)**

Drivers Medical Group

Longview Road

Swansea SA99 1TU

Tel: 0300 790 6806

[www.dft.gov.uk/dvla](http://www.dft.gov.uk/dvla)

[www.gov.uk/health-conditions-and-driving](http://www.gov.uk/health-conditions-and-driving)

*Information on medical rules for drivers.*

## General health:

### **NHS Choices**

[www.nhs.uk](http://www.nhs.uk)

NHS non-emergency line: 111

*Medical advice and information on health services.*



## Support groups

The Brain & Spine Foundation's online discussion forum is a space for people affected by a neurological problem or condition, their families and their carers to post messages, exchange views, share experiences and ask questions.

[www.brainandspine.org.uk/forum](http://www.brainandspine.org.uk/forum)

Cavernoma Alliance UK also provides an online support group.

[www.cavernoma.org.uk/members-area](http://www.cavernoma.org.uk/members-area)

## Further reading

The Brain & Spine Foundation produces a booklet with information on subarachnoid haemorrhage and fact sheets with information on brain and spine scans, angiogram, coiling of brain aneurysms, craniotomy, epilepsy, headache, migraine, stroke, TIA and clinical trials.

## References

Details of medical references used for this booklet are available at [www.brainandspine.org.uk/references](http://www.brainandspine.org.uk/references) or on request from the Brain & Spine Helpline: 0808 808 1000.

## Thank you

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# Brain & Spine Foundation

Our mission is to improve the quality of life of people affected by neurological problems by providing expert information, support and education. We rely on donations to provide our services to anyone who needs us.

## How to donate

- Online: [www.brainandspine.org.uk/donate](http://www.brainandspine.org.uk/donate)
- By phone: 020 7793 5900
- By post: send a cheque to the address below

## Contact us

Brain & Spine Foundation  
LG01 Lincoln House, Kennington Park, 1-3 Brixton Road,  
London SW9 6DE

Telephone (switchboard): 020 7793 5900  
[info@brainandspine.org.uk](mailto:info@brainandspine.org.uk)

Helpline: 0808 808 1000  
[helpline@brainandspine.org.uk](mailto:helpline@brainandspine.org.uk)

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