Vascular malformations of the brain

Brain & Spine Foundation

A guide for patients and carers
The Brain and 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.
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 Subarachnoid Haemorrhage booklet and Coiling of Brain Aneurysms fact sheet 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 abnormal arrangements of some of the blood vessels in your 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.

Vascular malformations usually occur on their own but it is possible to have more than one.

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

The main types of vascular malformation of the brain:

- Arteriovenous malformation of the brain
- Arteriovenous fistula of the dura
- Cavernous malformation
- Developmental venous anomaly
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 of the body which carry oxygenated blood away from the heart, towards the capillaries and to all parts of the body.

**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.

**Veins:** the thin-walled blood vessels of the body which carry deoxygenated blood back to the heart and lungs.
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 AVM is the complex tangle of arteries and veins which develops when the capillaries are missing in one area. Occasionally, doctors will use the more old-fashioned names, angioma or arteriovenous anomaly, to describe an AVM.

The knotted tangle of blood vessels in an AVM is known as a nidus (the Latin word for ‘nest’).
Occasionally, only a single artery and vein are involved, forming a particular type of AVM called an **arteriovenous fistula (AVF)**.

In cases of AVMs and AVFs, blood flows at high pressure from muscular arteries directly into thin-walled veins via the shortcut created by the absence of capillaries that would usually slow it down. 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 fibrous outer covering, the dura mater or **dura**. An example of a dural AVF is the **carotid-cavernous fistula (CCF)**.

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

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

**Dura**: the tough, fibrous membrane which forms the outer covering of the brain; the dura mater.

**Carotid-cavernous fistula (CCF)**: 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.
Common questions

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?
A cavernous malformation is a small, round cluster of abnormal, enlarged blood vessels. It is purple and resembles a blackberry. Some doctors might call it a cavernoma, a cavernous angioma, or a cavernous haemangioma.

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

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

What causes cavernous malformations?
A genetic cause has been identified for some people affected by cavernous malformations and they can occur in different generations of the same family. These families experience a mutation in a gene on the seventh chromosome. Cavernous malformations usually occur on their own but the people in these families often have several cavernous malformations.

We do not yet know why cavernous malformations occur in people who do not have relatives who have also been affected. However, 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 a dilated (widened) vein, a cluster of dilated veins, or a vein that takes an unusual course. Some doctors might call them 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. This is largely because, if they are discovered in adulthood, they very rarely seem to cause any problems for the people with them.

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 TIA (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 on stroke and TIA for further information.)
Developmental venous anomalies are sometimes associated with a nearby cavernous malformation which might be the cause of any symptoms.

**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 6).

A genetic cause has been established for cavernous malformations in some families. This is very unlikely if you only have one cavernous malformation.

**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?

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 that 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 headache, nausea (feeling sick), vomiting (being sick) and loss of consciousness.

Main symptoms of stroke

- 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
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 brain scan. 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 on 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 2% in any given year. If someone has had a bleed and received no treatment, the risk of subsequent bleeds is higher but it varies according to the exact location of the AVM and the way the veins drain from it. The risk of dying from a bleed might be as high as 1 in 5 (20%) and the risk of physical disability after a bleed might be as high as 1 in 3 (30%).
- The risk of bleeding from cavernous malformations and dural AVFs is much lower, probably less than 1 in 100 (1%) in any given year. The risk is even lower again for developmental venous anomalies.

It has not been reliably established whether there is an increased risk of bleeding from any type of vascular malformation during pregnancy, either due to increased blood circulation during pregnancy or blood pressure changes during labour.
Common questions

Epilepsy

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

(You might like to read out fact sheet on epilepsy for further information.)

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

• For people with a cavernous malformation, in any given year the risk of developing epilepsy is 1 in 100 (1%).
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.

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 dura membrane.

If drowsiness, unconsciousness or any stroke-like symptoms (see page 10) accompany a headache you should seek medical attention because of the possibility of a brain haemorrhage.

(You might like to read our fact sheets on headache and 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

A dural AVF 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.
Common questions

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.

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 vascular malformations of the brain probably do not directly cause psychological changes, it is quite common for people with them 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. It might also be helpful to contact one of the organisations listed in the Useful Contacts section (see pages 31-34).

Other symptoms
Other symptoms of vascular malformations of the brain might include speech problems, weakness in the arm or leg, balance problems, and enlarged blood vessels on the scalp.
Tests and investigations

CT scan

A CT scan is a Computerised Tomography scan. It is a special type of X-ray which 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 quick and painless examination.

A CT scan might be the first test used to diagnose a vascular malformation. Often, an MRI scan and/or an angiogram 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 (see below). A special dye (contrast agent) is injected into a vein in your arm and flows around your blood stream to highlight the blood vessels in your brain.
Tests and investigations

MRI scan

An MRI scan is a Magnetic Resonance Imaging scan. It 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 in a long tube. The scan is painless but, unfortunately, the scanner is very noisy. Earplugs or headphones are provided. Some people find the confined space in the scanner tunnel claustrophobic.

An MRI scan usually provides more detailed information about brain AVMs than a CT scan. It is the most accurate test for a cavernous malformation and different settings on the scanner (gradient echo sequences) can be used to confirm whether someone has a cavernous malformation and whether there is just one or several.

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 (contrast agent) is injected into a vein in your arm and flows around your bloodstream to highlight the blood vessels in your brain.

(You might like to read our fact sheet on 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 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 test is carried out in the radiology department. After you have had a local anaesthetic, a very thin, flexible tube (catheter) is inserted into the blood vessel in your groin (the femoral artery). This is passed through other blood vessels in your body until it reaches your neck. You will not feel it moving inside you.

The tube will be positioned into different blood vessels in your neck. While this happens, you will receive injections of a special dye (contrast agent) and several X-ray pictures are taken of the blood vessels in your brain as the dye passes through them.

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 tube was inserted to seal it and stop any bleeding.

An angiogram is usually the most accurate test for vascular malformations, although it does not show cavernous malformations at all. 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 on 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. Unfortunately, there is no treatment that can undo any damage that has already been done to your brain. Sometimes, the best policy for an individual is to have no treatment at all. There is a need for more research into the treatment of vascular malformations of the brain.

The main methods of treatment are **embolisation**, **stereotactic radiosurgery**, and **neurosurgery** (a craniotomy). You might have a one-off treatment, a combination of more than one treatment, or with embolisation, several separate treatments. Each vascular malformation is different and will require an individualised treatment plan.

**Embolisation**

Embolisation is used to treat AVMs of the brain and AVFs of the dura. It 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. A highly trained interventional radiologist who has considerable experience with the technique will carry out the procedure.
Embolisation can sometimes block off the blood supply to an AVM and get rid of it completely but it usually at least succeeds in reducing the size of the AVM. Sometimes, it can also 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 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. One or both of your groins might be shaved and 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 the AVM and place it in a safe position close to the AVM before injecting the liquid glue. The glue hardens after it is injected into your AVM and blocks the flow of blood through the AVM.

**What happens after embolisation?**

You will need to keep your legs straight to prevent bleeding at the point where the catheter entered the blood vessel in your groin.
Possible treatments

You will be observed closely by the medical team looking after you. Because there is a risk of stroke after embolisation, you should mention any unusual feelings if you develop them, although symptoms are likely to be short-lived. Many people experience a headache for a short while after the treatment. 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 in stages 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 22). However, it is less likely to seal off an AVM completely in just one go and you might need several separate sessions of treatment.

Stereotactic radiosurgery

Stereotactic radiosurgery uses radiation to treat small vascular malformations, mainly AVMs with a nidus less than three centimetres across. Currently, there is insufficient evidence that it can be used to treat cavernous malformations. It involves a single treatment of invisible, high-energy X-ray radiation, delivered by a machine called a linear accelerator (linac) or gamma knife. It is designed to target a high dose of radiation at your vascular malformation, minimising the effect on the surrounding areas of your brain and other parts of your body. Despite its name, the treatment is not a surgical procedure and does not involve any incisions.
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 X-ray beams precisely. For some forms of radiosurgery, you will need to be measured and fitted for a special frame that helps keep your head very still during the treatment. Staff will need to make an impression of your teeth and the back of your head well in advance to prepare for this. You might need to have a dental check-up.

You might also need to have some more scans before the treatment. These will provide detailed computer images of your brain which the radiotherapist and physicist will use to direct the X-ray beams accurately.

What happens during radiosurgery?
When you arrive for your treatment, your customised head frame will be fitted (if necessary). Its measurements will be checked again and X-ray pictures will be taken to confirm its exact position. You will then lie on a couch that supports your head and the frame. The radiographers will set up the positions of the couch and the X-ray machine.

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 X-ray machine.

What happens after radiosurgery?
After the treatment, it can take three or more years for the vascular malformation to seal up and disappear. During this time, you remain at risk of experiencing symptoms caused by your
Possible treatments

vascular malformation. After this time, your doctors might want to repeat an angiogram or MRI scan to see how effective the treatment has been. Sometimes, radiosurgery does not succeed in sealing up the AVM.

The advantages of radiosurgery are that it does not involve neurosurgery (see below) or a general anaesthetic and it can be used to treat some vascular malformations located deep in the brain which are otherwise hard to reach. However, it cannot usually be used to treat vascular malformations larger than three centimetres across and it does not always seal up the AVM. There is also a risk of the radiation damaging the surrounding brain tissue (radionecrosis).

Neurosurgery (craniotomy)

Neurosurgery is surgery on the brain or spine. Surgery to open the head and operate on the brain is called a craniotomy. Craniotomy is the longest established treatment for vascular malformations of the brain. It is usually used to treat AVMs of the brain, and sometimes AVFs of the dura, by disconnecting the AVM from the arteries that supply it with blood and the veins that drain it. Craniotomy is sometimes also used to remove cavernous malformations.

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.

What happens before a craniotomy?

You will be admitted to hospital the day before your surgery is scheduled. Usually, your fitness for a general anaesthetic will have been assessed with a thorough examination, blood tests, and possibly a recording of your heart rhythm. You will not be allowed to eat for
six hours or drink for two hours before the operation. An anaesthetist will give you a general anaesthetic on the day of your surgery so you will be asleep before you are taken into the operating theatre.

**What happens during a craniotomy?**
The team of health professionals looking after you will include one or more neurosurgeons, an anaesthetist, and theatre nurses. An area of your hair 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 like a trapdoor to reveal the brain and vascular malformation underneath. An AVM will then be carefully detached from the surrounding blood vessels. This can take several hours.

**Craniotomy incision and replacement of the bone flap**

![Diagram](image.png)
Possible treatments

What happens after a craniotomy?
The bone flap is replaced and the scalp is stitched together. The bone flap is usually fixed into place with small metal screws to prevent movement and encourage better healing. You will be taken to a recovery area, usually in the intensive care unit, where you will be under close observation. Shortly after you have woken up from the anaesthetic, you will be transferred back to the ward. You can expect to leave the hospital within a week or ten days, if you are not experiencing any problems.

After the surgery, you might experience epileptic seizures for the first time. If you have already had them, they might improve or worsen. 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 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 radiosurgery and could only be partially treated with embolisation. However, surgery requires a general anaesthetic which has its own risks and some vascular malformations deep in the brain cannot be reached safely with a craniotomy. Surgery to remove a vascular malformation carries a risk of stroke as a result of the procedure.

(You might like to read our fact sheet on craniotomy for further information.)
Other treatments

Drug treatment

You might be given steroids to reduce any swelling in the brain around the vascular malformation before 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 or bleeding from an AVM 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, page 33). 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.
Everyday activities

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 if it is safe 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, so they are an important subject for medical research.

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 on 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 like 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.

Occupational therapist: a specialist health professional who offers practical support and advice on everyday skills and activities like washing, cooking and using equipment at home.

Counsellor: a person trained to give guidance on personal, emotional and psychological problems.
Useful contacts

**Vascular malformations of the brain:**

**Brain and Spine Helpline**
Brain and Spine Foundation
3.36 Canterbury Court
Kennington Park
1-3 Brixton Road
London SW9 6DE

**0808 808 1000**
**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 Charity)**
Brain and Spinal Injury Centre
554 Eccles New Road
Salford M5 5AP

**0870 750 0000**
**www.basiccharity.org.uk**

Support and information on neurological conditions.

**Neurosupport**
The Neurosupport Centre
Norton Street
Liverpool L3 8LR

**0151 298 2999**
**www.neurosupport.org.uk**

Support and information on neurological conditions.
Useful contacts

**AVM Support UK**  
Suite G03  
Blyth CEC  
Ridley Street  
Blyth  
Northumberland NE24 3AG  
www.avmsupport.org.uk  
Support and information on AVMs.

**Cavernoma Alliance UK**  
(based in Dorset)  
www.cavernoma.org.uk

**Epilepsy:**

**Epilepsy Action**  
New Anstey House  
Gate Way Drive  
Yeadon  
Leeds LS19 7XY  
0808 800 5050  
www.epilepsy.org.uk  
Support and information on epilepsy.
National Society for Epilepsy
Chesham Lane
Chalfont St Peter
Buckinghamshire SL9 0RJ
01494 601 400
www.epilepsysociety.org.uk
Support and information on epilepsy.

Stroke:

Stroke Association
240 City Road
London EC1V 2PR
0303 303 3100
www.stroke.org.uk
Support and information on stroke.

Driving:

DVLA (Driver Vehicle and Licensing Agency)
Drivers Medical Group
Longview Road
Swansea SA99 1TU
0300 790 6806
www.dft.gov.uk/dvla
www.direct.gov.uk/motoring
Information on medical rules for drivers.
Useful contacts

Flying:

Aviation Health
17c Between Towns Road
Oxford OX4 3LX
01865 715 999
www.aviation-health.org
Information on health and flying.

General health:

NHS Choices
www.nhs.uk

NHS Direct
0845 46 47
Medical advice and information on health services.
Support groups

The Brain and Spine Foundation’s online discussion forum offers the opportunity to post messages, exchange views, share experiences and ask questions.

www.brainandspine.org.uk/applications/discussion

AVM Support UK and Cavernoma Alliance UK provide online support groups.

Further reading

The Brain and 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 or on request from the Brain and Spine Helpline 0808 808 1000.
Thank you

We would like to thank everyone who contributed to this booklet, especially Rustam Al-Shahi Salman (MRC Clinician Scientist and Honorary Consultant Neurologist), Stefan Brew (Consultant Neuroradiologist), Sarah Davis (Neurovascular Clinical Nurse Specialist), Fergus Robertson (Consultant Neuroradiologist), Ann Taylor (Superintendent Radiographer), Jan Harrington (AVM Support UK), and Ian Stuart (Cavernoma Alliance UK).
The Foundation provides support and information to those affected by the many conditions associated with the brain and spine. The charity relies heavily on voluntary donations and fundraising events to provide the services which have helped many thousands of people across the UK.

You can help the future work of the Brain and Spine Foundation by

• Making a donation
• Organising or taking part in a fundraising event
• Offering your time as a volunteer
• Remembering the Brain and Spine Foundation in your will

Further details available from the address/telephone number below or from www.brainandspine.org.uk.

Brain and Spine Foundation
3.36 Canterbury Court, Kennington Park, 1-3 Brixton Road
London SW9 6DE
Telephone (switchboard): 020 7793 5900
Helpline: 0808 808 1000
www.brainandspine.org.uk
Registered Charity Number: 1098528

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Do you need more help or information?

We hope you found the information in our booklet useful. If there’s anything you are still unclear about, or if you’d like to ask a question, please feel free to contact our Brain and Spine Helpline.

The neuroscience nurses on our Helpline are available to talk things through with you - call free on 0808 808 1000 (weekday mornings) or email us at helpline@brainandspine.org.uk.

The Helpline covers all brain and spine conditions and can offer information and support on any medical or related social and emotional issues of concern.

Can you help maintain this service with a donation?

Our information services are free, but we rely heavily on donations in order to keep publications like this one, as well as our Helpline and website available to people affected by brain and spine conditions. Any amount you can spare, however small, will be very gratefully received - thank you.

3 ways to donate:

- Click www.brainandspine.org.uk/donate
- Send a cheque to Brain and Spine Foundation, Freepost LON10492, London SW9 6BR
- Or call us on 020 7793 5900 (office hours)