Patient Information

BRAIN ARTERIOVENOUS MALFORMATION (AVM)
What is a Brain arteriovenous malformation (AVM)?

A brain AVM is a tangle of abnormal and poorly developed blood vessels connecting arteries to veins.

AVM's are rare and occur in less than 1% of the population.

In normal situations arteries take oxygen rich blood away from the heart to various parts of the body under high pressure and so have strong muscular walls. These arteries flow into small capillaries. Capillaries are the tiny blood vessels that deliver oxygen-rich blood to tissues and carry away waste products. The blood from arteries is slowed down through this capillary network. Capillaries then flow into veins to take the blood back to the heart. Veins have thinner walls because they take blood back to the heart under lower pressure.

In an AVM this process is disrupted by the tangle of abnormal and poorly formed blood vessels. This tangle is referred to as the ‘nidus’ of the AVM.
**What causes an AVM?**

The cause of AVM is not known. It is thought that in most cases they are formed during development before birth or shortly afterwards although it usually takes some time before they cause problems or symptoms.

AVM’s are not cancerous or infectious and don’t spread to other parts of the body.

AVM’s affect men and women equally.

Most are discovered between the ages of 20-40.

Rarely AVM’s run in families and a genetic cause can be found. This inherited condition is called hereditary haemorrhagic telangiectasia (HHT).

**Types of AVM**

- AVM’S can occur anywhere in the body but those in the brain are of particular concern because of the problems they cause if they bleed.
- The classic more common type is made up of the blood supply to the brain and called a pial AVM.
- Occasionally, only a single artery and vein are involved, forming a particular type of AVM called an arteriovenous fistula (AVF). Arteriovenous fistula’s can, however, involve more than one connection.
- A dural AVM is more commonly called a dural AVF (dAVF) and involves one or more abnormal connections between an artery and a vein. This is a less common type of AVM and may form as a result of head injuries, brain surgery, infections of the brain, or blood clots in the large veins that drain the brain although sometimes no obvious cause is found.
- The size of AVM’s varies from person to person. Some are small, but others can cover large parts of the brain.
- Most AVM’s don’t grow or change much, although the blood vessels involved may dilate (widen) making them bigger. Less often they shrink if the blood clots in a part of the AVM.
Symptoms of an AVM

In about 15% of cases AVM's don't cause symptoms and are found incidentally.

**Seizures:** In approximately 20% of cases they are found because of seizures. Seizures occur because AVM's can be irritant to the brain. 1% of people who have AVM's are at risk of seizures.

**Haemorrhage:** More than 50% of AVM's are discovered following haemorrhage. Symptoms include a sudden onset of severe headache often with nausea, vomiting, stroke like symptoms or a decreasing level of consciousness. The blood vessels in an AVM are weaker and so have a higher risk of bleeding than normal ones.

Bleeding is the most serious complication of an AVM and is the main reason for recommending treatment.

The risk of bleeding is approximately 2-3% each year although is slightly higher in the year following a bleed (4-6%). Some bleeds cause mild symptoms but approximately 50% are significant.

**Headaches:** Headaches may be caused by the high blood flow through the AVM. These headaches may be similar to a migraine or be actual migraines. They can be mild or disabling.

**Stroke:** Brain AVMs may cause stroke-like symptoms by depriving the nearby brain tissue of oxygen and nutrients. The symptoms can include, weakness or paralysis on one side of the body; numbness and tingling; problems with vision, hearing, balance, memory and personality changes. Symptoms depend on the part of the brain the AVM is in.

Some AVM's can cause noises in the head as a result of blood flowing through it.
Diagnosing an AVM.

Computerised Tomography scan (CT scan): This can be done with or without dye to look for bleeding in the brain and to view the AVM.

Angiogram: A thin tube is inserted into an artery in the groin. This is passed through the blood vessels to those in the brain. Dye is then injected and X-ray pictures are taken. Doctors are able to see the exact location, shape and size of the AVM. It also shows if any other weaknesses are associated with the AVM such as blisters or aneurysms. An angiogram is essential to plan a management of the AVM.

Magnetic Resonance Imaging (MRI scan): An MRI scan is used to make a detailed picture of the position of the AVM in the brain in relation to other important structures and is used to plan management. If the AVM is close to important (eloquent) parts of the brain for example vision or movement, then a functional fMRI scan will be taken to map the pathways of these structures in relation to the AVM.

Transcranial magnetic Stimulation: Transcranial magnetic stimulation (TMS) is a procedure that uses magnetic fields to stimulate nerve cells in the brain. It is non-invasive which means it doesn’t involve needles or surgery. Small pulses of electric current are applied through a coil which stimulate and map certain parts of the brain in relation to the AVM and help the surgeon to make a treatment plan.
Treatment for AVM:

AVM's are complex and unique to each person. For this reason management is individual to each case.

Once the required tests have been completed your medical team will sit together with other experts and make the safest and most appropriate management plan for your AVM. This is called a multidisciplinary team (MDT) meeting.

Treatment depends on the size, shape, position and blood supply to and from the AVM. It also depends on the risks associated to local parts of the brain which may cause lifelong disability if damaged.

Treatment also takes into account your health and wellbeing along with your personal wishes if appropriate.

**No treatment plan will be made without discussing the options with you.**

Treatment for AVM:

Treatment includes surgery, endovascular procedures, radiosurgery or a combination of treatments. The risks of treatment are considered to be high for AVMs that are located in deep parts of the brain or with very important functions nearby.

Unfortunately some AVM's cannot be treated as the risk is too high. If this is your plan, you will be monitored with scans.

**Surgery:**

Whilst you are asleep under general anaesthesia in an operating theatre, your neurosurgeon removes a window of your skull temporarily to gain access to the brain and AVM. With the help of a high-powered microscope, the surgeon seals off the AVM and carefully removes it from surrounding brain tissue. The skull bone is reattached and the incision in your scalp is closed.

The risks of surgery will be discussed with you by your neurosurgeon and specific to the area of brain the AVM is in. The common risks are bleeding, stroke and seizures

Since AVMs do not grow back, the cure is immediate and permanent as long as the AVM is removed completely.

Following surgery you will normally go to the Intensive Care unit for close monitoring and to manage symptoms, including controlling blood pressure. Once you are stable you will go
back to the ward for further recovery.

When you are up and about and independent you can go home. Expect a recuperation period of up to three months off work depending on how you are and the type of work you do.

Recovery varies according to whether you have bled from the AVM and any after effects of the surgery.

You will be seen in clinic after 2-3 months. A follow up angiogram will usually take place once you have recovered. This is to confirm obliteration of the AVM. In rare circumstances, further treatment is needed to close any small remnants of the AVM.

There are driving restrictions after surgery but these are specific to the position of the AVM as well as ongoing symptoms and recovery. This is individual and so will be discussed with you before going home. Driving restrictions change all the time and dependent on your recovery. If you fully recover with no symptoms it is one month for cars.

* Surgery for AVM

**Stereotactic radiosurgery (SRS):**

Without entering the skull, SRS directs many highly targeted radiation beams at the AVM to damage the blood vessels and cause scarring. The scarred AVM blood vessels then slowly clot off following treatment. Radiosurgery takes about 2-4 years to work and is successful in up to 80% of cases although this figure varies with the size and shape.

Treatment planning for stereotactic radiosurgery includes a team discussion with the experts in radiosurgery.

Further planning investigations include angiogram, CT scan and MRI scan. You will also
need a mask making that fits over your head or have a frame attached to your skull for a short time in order that the beams of radiation are accurate and don’t damage healthy brain. The treatment itself only takes about half an hour. You may get small patches of hair loss afterwards but these will almost certainly grow back. You will have regular follow up afterwards. After 2 years you will have an MR scan to check on the AVM. If it can’t be seen you will normally have an angiogram to confirm it is completely gone (obliterated).

**Embolisation:**

Endovascular embolisation, involves the insertion of a tube or catheter through an artery in the groin in the same way as an angiogram except you will be asleep under anaesthetic. The tube is guided through the blood vessels to the site of the AVM, where it delivers a type of ‘glue’ that embolises (or blocks) blood flow to the malformed vessels.

Embolisation can used before surgery to make the AVM smaller and safer to take out surgically. Depending on the size and shape of the AVM, embolisation may be done in one stage or many.

Less often, embolisation is used to reduce the size of a large AVM sufficiently to make radiosurgery a viable option.

After embolisation you may go to the intensive care unit for close monitoring if needed. If you are well after the procedure you will go back to the ward to recover. As soon as you feel able, you can go home although you may need a further MRI scan afterwards to check on progress of treatment.

If you are having staged embolisation closely followed by surgery you may be able to go home in between if you are happy to and feel well enough.

If you have a number of treatments, each stage of embolisation affects you differently. You may feel very well after one or experience headaches or symptoms after another. Symptoms generally settle down.

You will usually have an angiogram when the treatment is complete and you have recovered. This is to check the AVM is sealed (obliterated).
Preparing for treatment.

If you are having treatment for your AVM, you will be seen in the pre-operative clinic by one of the neurovascular nurses who will assess your fitness for a general anaesthetic, explain the procedure and answer any concerns. The pre-operative clinic review takes approximately 1½-2 hours in total.

Bloods and measurements of height and weight will also be taken. Please bring a urine sample with you and a copy of any medicines you are taking.

Further tests may be necessary according to your general well-being and other medical conditions before a decision is made that you are fit for the anaesthetic procedure.

You will be assessed by an anaesthetist before the operation. The anaesthetist is the consultant doctor who administers the general anaesthetic and pain relief during the operation.

You should shower and wash your hair in the solution given to you in pre-op, as advised, before the operation in order to clean and reduce the risk of infection.

You will normally come in the same day as your surgery unless otherwise stated. You will be expected to make your way to the hospital for approximately 07:30 and present to Jefferson ward.

You should not eat anything from midnight before coming to hospital. You can sip water until you come in. You will be advised which medicine should be stopped or taken before your treatment by your pre op nurse.

Recovery:

Recovery is individual to each circumstance. It is often quicker if you have never had symptoms or minor symptoms from the AVM and when treatment is straight forward.

No matter how well you feel it is worth taking some time (for example a few weeks) to look after yourself after treatment if you are able. This would include time off work if you are able and enlisting the support of family or friends.

If you have bled or have experienced severe symptoms from the AVM, recovery will often take longer depending on how this has affected you. Like any injury to the brain, most of the recovery takes place in the first six months although it can take up to two years. In certain cases, individuals are left with long term problems such as weaknesses to parts of the body, problems with vision, speech or epilepsy. If there are any concerns or problems you will need assessment and rehabilitation from physiotherapists, occupational therapists...
and speech therapists whilst you are in hospital. This is to make sure you will be safe at home as well as supporting your independence and recovery. There are occasions a longer period of further rehabilitation is needed in a specialist unit which may delay going home.

Support can be enlisted from clinical psychologists in rehabilitation or as an outpatient as understandably, the whole events surrounding the AVM can be traumatic and on-going for some.

Recovery is dependent on how you feel and is individual to each person.

**Information if you have bled or have had complications from the AVM:**

You will need to pace yourself for the first month or more after going home because of tiredness and possibly headaches. Save your energy for the things you have to do and those you want to do. Looking after yourself in the early days of recovery is beneficial to your well-being in the long term. You may benefit from gentle exercise as well as a short rest each day in the early days of your recovery.

Feelings of anger, frustration and sadness are not uncommon following a brain haemorrhage. This may be due to the condition but could just as well be due to the sudden life changing event and usually passes with time. If you are affected, you should talk to your GP as you may benefit from being referred to a psychologist to help you through this stage of recovery.

Enlist the support of your family and friends whilst you recover. They will be a great help with shopping, transport and support and will be the biggest influence in your successful recovery.

It is advised to have someone stay with you for the first week or so after going home.

**Information if you have had seizures from the AVM:**

If you have had a seizure from the AVM you may need specialist management. One seizure does not count as a diagnosis of epilepsy. A diagnosis of epilepsy is usually made by a specialist neurologist who will manage these symptoms, often through medication. For your peace of mind and safety, you and your family need to be educated on how to manage the types of seizures you have and what to do if one occurs at home. Information
is available for all patients who have epilepsy or have had seizures. This would be through your ward staff, the epilepsy nurse specialist team or the neurovascular nurse specialist team. The epilepsy nurses give a great deal of support including a dedicated phone line.

**Living with AVM:**

Symptoms caused by AVM’s are many and specific to each individual. You may find that many symptoms are made worse if you are tired, under stress or ill. This is particularly so if you experience seizures, headaches or have bled from the AVM. People with large AVM’s that can’t be treated also experience this. Factor this into your recovery as you may need to look after yourself a bit more or ask for some help during these times.

Lifestyle is important when recovering. Lifestyle choices can make you feel worse or better. Gentle exercise as you are able, eating well and preventing dehydration all help symptom control. Getting the right amount of sleep helps; too much or too little sleep can make you feel worse.

If you do too much, you may feel a little worse that evening or the next day. The general rule is if you want to do something and feel able to, then you can. If you find this makes you tired, then plan an easy day afterwards!

**Memory problems:** memory problems are common in people with AVM’s. If you have had a haemorrhage from it you may be left with problems with your short-term memory, attention and concentration. A lot of people report poor memory, even if they haven’t had a bleed from the AVM. This may be due to changes in blood flow or made worse by worry, other illnesses or tiredness.

**Visual problems:** visual problems can occur because of the effects of certain AVM’s. These can present as blurred vision, double vision, partial or very rarely, complete loss of vision. Assessment and help can be gained if you have visual problems through an eye doctor called an ophthalmologist. If your vision is affected so that you can’t drive, it is likely you will be able to apply for a free bus pass.

**Noises in the head:** Certain types of AVM can cause noises such as pulsating or whooshing noises due to the blood flowing through the AVM. If the noise gets worse or stops you should contact your doctor or the hospital urgently.

**Extreme tiredness:**

You will probably need rest once you get home particularly if you are having a lot of visitors or your house is very busy. Even simple tasks such as a walk to the local shop may leave
you feeling exhausted. This will improve with time. You will know if you have done too much as you will be exhausted and may experience more headaches. This often happens early evening or the next day and means you have to take a rest! Pacing activities as well as regular exercise will help.

**Headaches:** Headaches are common and can persist with AVM’s. If your headaches started after a bleed or treatment then they may ease with time. Headaches can be triggered by dehydration, stress, illness, too much or too little sleep and missing meals. Drinking 2 litres of water a day should help reduce the frequency and severity. Also, try and get back to a normal sleep pattern as soon as possible. Try putting some structure into your day, including meal times as this will help with headaches and recovery. Stopping smoking and reducing the amount of caffeine you take may help reduce the severity of headaches. Menthol sticks to rub on the forehead can help. Drinking a pint of water at the start of a headache may also help. Taking regular pain medication can also make headaches persist and so should be reduced as soon as you are able.

If headaches persist and are troublesome you may need specialist management. This is particularly so if you are still taking regular pain medication after a few months.

**Everyday activities:**

**Driving:** You must inform the DVLA if you drive and have an AVM. Driving restrictions are specific to the position of the AVM, the treatment and whether it has bled or not. You must speak to your medical team or nurse to clarify driving restrictions.

**Sport and swimming:** Exercise is encouraged as it improves stamina and wellbeing. Most sports can be resumed once you feel able and any wounds have healed. You should build up your fitness slowly as you feel able. Extreme exercise and contact sports are normally avoided until the AVM has been proven to be obliterated and you feel fully recovered. If you have had surgery, you will need to avoid contact sport and wear suitable head protection with certain sports. This is because the area where the bone has been removed and replaced will be weaker.

Taking a companion and letting the lifeguard know is advisable if you have epilepsy, had treatment for you AVM or for the first year after a bleed.

**Flying:** Flying is not advised in the first six weeks following surgery. You should inform your holiday insurance company that you have an AVM.

**Returning to work:**
This depends on the job you do, how you are and whether you need a car to work. Most people benefit from some time off to recover and look after themselves. It is advisable to
go back to work on a phased return. The length of time you need to recover is dependent on what has happened and what treatment you have had. Your neurovascular nurses will advise discuss this with you.

**Washing and dying hair:** You can wash your hair with mild shampoo 3 days following surgery but you cannot dye it until the wounds have fully healed.

If you have had an embolisation procedure, you can wash and dye your hair as soon as you wish.

If you have had SRS then you can wash your hair with mild shampoo as soon as you are able. It is advisable not to dye the hair if there are patches of hair loss; you can dye it once the hair has regrown.

**Alcohol:** It is best to drink in moderation according to government guidelines. If you experience seizures, there is a risk of provoking one if you drink too much. If you are taking medication, you should check with your doctor if it is safe to drink alcohol.

**Illicit drugs:** We recommend that you do not take illicit drugs such as cocaine and amphetamines. These can artificially increase blood pressure for long periods of times which isn’t recommended with AVM’s.

**Sex:** you can have sex as soon as you feel able.

**Pregnancy:** There is a very small increased risk of haemorrhage from an AVM during pregnancy; this is generally after the first three months and is thought to be due to the increased blood circulation that occurs during pregnancy.

If treatment is planned it is better to wait until after the AVM is obliterated before planning pregnancy.

Reassuringly, lots of women have successful uncomplicated pregnancies without knowing they have an AVM.

If you become pregnant with an AVM that isn’t obliterated then we would recommend that the second stage of labour isn’t prolonged. Your obstetrician may want to speak to your neurosurgical consultant with regards to this so that they can plan a safe delivery for you and your baby.
ADVICE FOR CARING FOR PUNCTURE SITE IF YOU HAVE HAD AN ANGIOGRAM OR EMBOLISATION PROCEDURE.

If the problem is considered serious, help should be sought from your local accident and emergency department immediately. Otherwise, you should contact your G.P., NHS direct or visit your local walk in centre.

- Do not strain or lift anything greater than 10lb for 7 days following angiogram
- Drink plenty of water or juice 24 hours before and 24 hours after the angiogram to prepare the kidneys and flush the dye from your body (about 2 litres or 10 glasses)
- Do not drive or operate machinery for 24 hours following angiogram
- Do not do any physical exercise or sexual activity for 24 hours following the angiogram.
- Keep the dressing on, clean and dry for 24 hours following the angiogram
- After 24 hours the dressing can be removed and a shower (not bath) can be taken.
- Clean and inspect the site and wash with mild soap and water. Dry and re-cover with a plaster until it is healed completely
- A bath and swimming is allowed once the site is fully healed.
- Report to your doctor if the site bleeds and not stopped after 10 minutes of firm (but not excessive) manual pressure.
- Report to your doctor if there is any swelling, change in colour (paler or darker) or change in sensation to the leg.
- Report to your doctor if there are any signs of infection such as redness, pain, swelling or pus from the site.
- Report to your doctor if there are signs of excessive new bruising (a small amount of bruising is expected from the procedure)

Contact details for verbal advice following angiogram;
Verbal advice is available 24 hours a day / 7 days a week.
Walton Centre Contact Details

For any emergency see your G.P or your go to your local Accident and Emergency Department

For information regarding appointments or DVLA contact your Consultant’s secretary

Patient Experience Team provides a PALS service. 0151 529 6100

Neurovascular Nurse Specialists: 0151 556 3325
   Or through hospital switch.
   (Non-urgent enquiries – calls may not be answered the same day)

Walton Centre switchboard - 0151 525 3611

Dott Ward - 0151 529 5633 / 5634

Cairns Ward - 0151 529 5637 / 5638

Caton Ward - 0151 529 5628 / 5629

Sherrington Ward - 0151 529 5641 / 5642

Chavasse ward - 0151 529 5070

Lipton Ward - 0151 529 8884 / 8738

High dependency - 0151 529 5489

Intensive Care - 0151 529 5772/ 5773
Useful Contact details

NHS 111: 111
Telephone advice if you need urgent medical help fast but it is not a 999 emergency (or you do not have a GP)
Website: http://www.nhs.uk and search ‘emergency and urgent care’

D.V.L.A. Driver Vehicle Licensing Authority,
Drivers Medical Group, DVLA, Swansea, SA99 1DL.
Medical Enquiries: 0843 116 0011
Email via www.dvla.gov.uk

Brain Haemorrhage Support Group affiliated to Walton centre:
bhsupport@live.co.uk
Facebook or via Brain Charity

The Brain Charity: 0151 298 2999. www.thebraincharity.org.uk

Working Life Service at The Brain Charity: 0151 298 3288

Department of Work and Pensions: 020 7712 2171
www.awp.gov.uk

NHS Free smoking helpline: 0300 123 1044 or www.smokefree.nhs.uk

Advice on Alcohol: www.drinkaware.co.uk or www.drinkingandyou.com

Notes: