Patient Information

ENDOVASCULAR EMBOLISATION OF 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 vessels that deliver oxygen-rich blood to tissues and carry away waste products. The high flow 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 low 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 and occur in all races.

Most are discovered between the ages of 20-40.

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

AVMs are rare and occur in less than 1% of the population.

**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.

A dural AVM is more commonly known as a dural AVF (dAVF) and involves one or more connections between an artery and 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. 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, neurological problems or a decreasing level of consciousness. The blood vessels in an AVM are weaker and so at 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 2-4% each year. This risk is slightly higher in the year following a bleed.
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.

Dural AVF’s can cause headaches because of the many pain fibres on the surface of the brain being irritated.

**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 the blood flowing through it. Dural AVFs may cause tinnitus which is a whooshing noise in time with the pulse.

**Embolisation of AVM:**
An endovascular embolisation procedure is a way of sealing off an AVM so that it is no longer at risk from bleeding. This procedure uses special materials such as particles, glue or coils which are designed to reduce or block the flow of blood through the AVM in order to seal it off.

It involves the insertion of a tube or catheter through an artery in the groin (femoral artery) or wrist (radial artery) in the same way as an angiogram except you will be asleep under general anaesthetic.

In some cases two catheters are used in the right and left groin. More rarely additional veins in the neck or the eye for example can be used to access the AVM.

The tube(s) is/are guided through the blood vessels to the site of the AVM, where they deliver the materials to block the AVM. Depending on the size and shape of the AVM, embolisation may be done in one stage or many.

Embolisation can be used on its own or before surgery to make the AVM smaller and safer to take out surgically.

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

The length of time the procedure takes depends on what is done and how complicated it is; this is individual to each person as every AVM is different.
What happens before the procedure?

You will be invited to pre op clinic to be assessed and allow you to ask questions regarding the procedure. This clinic visit usually lasts up to 2 hours as a detailed clinical history and examination takes place and tests completed to ensure your safety for the procedure and anaesthetic.

Please bring a list of your medicines and your medical history with you.

You should drink 2 litres of water 2 days before the procedure and the day before. This is to prepare your kidneys to flush out the dye used during the procedure.

You normally come in the same day as the procedure at 7am in the morning unless there are plans for you to come in the day before. You should make your way to your assigned ward.

If you have certain medical conditions, you may need to come in the day before.

The night before the procedure you should not eat any food from midnight. You can sip water until your procedure. You should take your normal medicines in the morning unless you have been told to withhold them at pre op.

Every effort is made so that you can have your procedure on the planned day but unfortunately, if another patient comes in as an emergency, your procedure may need to be postponed.

Emergencies will always take priority.

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Although you may not need one; if there are no intensive care beds your procedure will be cancelled as your safety is our priority.

We will make every effort to prevent cancelling your procedure. If it is cancelled, you will normally go home and return a second day. In some cases, you will be kept in if the procedure can be facilitated the next day.

**What are the risks of the procedure?**

The procedure will not be carried out unless the benefits outweigh any possible risks. You will have discussed the procedure and risks with your neurosurgeon/ interventional neuro-radiologist and given your consent before you go ahead with the procedure.

The common risks are complications that include stroke-like symptoms such as weakness or numbness in an arm or leg; problems with speech or problems with vision.

AVMs are weak blood vessels and so there is a rare chance that they bleed during the procedure: sometimes this means you have to go on to have neurosurgery through the skull to remove the blood or the AVM.

There is also a risk of bleeding, infection or arterial damage at the entry site in the groin or wrist. Sometimes arterial damage such as a small tear occurs at another place in your body or brain. In rare cases reparative surgery is needed if the artery in the groin or wrist is damaged.
There is a small risk associated with the radiation (x-rays) used to treat AVMs. We are all at risk of developing cancer during our lifetime: The normal risk is that this will happen to about 50% of people at some point in their life. Radiation received from undergoing this type of intervention will increase the chances of this happening to you from 50% to somewhere in the range of 50.01% to 50.0001%

**Hair loss**

Very rarely small patches of hair loss can occur after any treatment involving x-rays. The hair usually grows back.

If you do lose some hair, you should use gentle shampoo only and not use strong chemicals such as dyes, perms and strong hair products

If this happens to you, you should let us know.

**What happens after the procedure?**

After your AVM is treated, you will spend some time in the post-operative care unit (POCU) to wake up safely from the anaesthetic.

You will be assessed and go to a ward once it is safe to do so. Sometimes it is necessary for you go to the intensive care unit where there are more facilities to treat and monitor you: This may be because the procedure was long, complex or certain treatment is necessary such as making sure your blood pressure is kept low to allow the blood vessels in the brain to heal. **This is the reason**
we do not normally start a procedure if there are no critical care beds.

You may wake up with drips in your hands, arms and/or feet.

You may also have a catheter inserted in your bladder to drain urine (if you are well, you can request this is removed by the recovery or ward staff).

If you are well and your blood pressure is OK, you may go back to the ward to recover

**Once back on the ward or intensive care unit, you will need to lie down on bed rest for 6 hours.** This helps to minimise the pressure on the artery that has been used to access the AVM.

You will have regular observation of your limb strength, conscious level, blood pressure and pulse, as well as the puncture site. You will have a drip to make sure you don’t get dehydrated. Once the drip is out we will expect you to drink plenty the next day to wash out the contrast (dye) used in the procedure. You will have stockings and compression devices on your legs.

You may have blood thinning injections after the procedure until you go home. This is to prevent venous clots (D.V.T.’s) in your legs whilst you aren’t moving around as much. These are discontinued when you get home.

You will be allowed to gradually sit up after 6 hours and gently mobilise with supervision if the nurse looking after you feels it is safe to do so.
The puncture site in your groin will need to be checked regularly. It is sometimes a little bruised and painful afterwards. A small amount of bruising is common but if it is excessive you must let your medical or nursing team know. The site should not bleed afterwards.

It is advisable to hold the puncture site area whilst coughing or straining afterwards if possible. Very rarely the puncture site can be damaged during the procedure or afterwards and may need further intervention or surgery to fix. You should let someone know if it doesn’t feel right or you have pain in your leg or flank area of your tummy.

**Instructions on looking after the puncture site are included towards the end of this booklet.**

**Going home:**

Once your medical team are happy that you no longer need treatment you will be allowed to go home. This is often the day after the procedure if there are no complications. It may, however, be longer if you need extra monitoring or recover more slowly.

You may need an MRI scan before you go home 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.
Recovery:

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.

It must be remembered that whilst there are no scars, the blood vessels suppling the brain have been disrupted and so you may need time to recover from the procedure.

**Headaches**

You may get headaches for the first few days after the embolisation procedure. These usually ease after a few days to weeks.

Simple medication such as paracetamol should help. Headaches can be triggered by dehydration, stress, illness, too much or too little sleep and missing meals. Drinking 2-3 litres of water a day, regular meals, ensuring good sleep pattern and in some instances avoiding certain triggers (caffeine, alcohol, milk, cheese etc) can help. There are also some options such as menthol sticks to rub on the forehead that should help reduce the frequency and severity of headaches. Prolonged or regular use of analgesia (paracetamol, ibuprofen, codeine, morphine etc.) may also worsen or prolong headaches so should be used sparingly and stopped if no longer required.

**If the headache gets worse or does not improve you should seek medical advice and let us know**
Pacing:

Recovery is helped by pacing your activity for the first week or so following going home. Take a daily rest as well as some gentle exercise. Build up activity as you improve.

Returning to work:

You can return to work as soon as you feel able although most people need about 2 – 4 weeks off to recover. (Occasionally more if there have been complications)

Unusual sensations:

Some people experience unusual sensations in their head following treatment. Some examples are ‘cotton wool’ sensation or ‘water trickling’. We are not sure why this occurs, but they should ease with time.

Fear of the AVM bleeding:

This is a very common fear for a lot of patients. Unfortunately the risk is real but it is extremely small. It is important to learn a coping strategy. You will have an angiogram to confirm obliteration of the AVM and will only be discharged from the Walton Centre when we think it safe to do so.
Follow up:

You will have your first follow up visit a couple of months after you go home. This visit is usually in the nurse clinic where you will be given the opportunity to discuss your recovery.

If you need further treatment then you will see the medical team to plan this.

Your follow up will include another angiogram in order to check if the AVM has been fully occluded.

You may also have further scans at a later date although this is individual to each person.

Commonly asked questions.

Driving

You cannot drive for a month following an embolisation procedure. You do not normally have to inform the DVLA unless there are complications with vision, stroke. Or the AVM bleeds.

DVLA guidance changes regularly and so you should always check driving instructions with your medical or nursing team before you go home.

When you drive again, you should go out on a quiet road on a quiet day to see how you manage. This is because driving involves many different cognitive and physical skills as well as multi-tasking, decision making and problem solving.
Flying

If you have had embolisation (but no surgery), you should be able to fly as soon as you feel able. It is safe to go through the metal detectors in the airport.

Smoking Cigarettes

If you smoke, you should use this opportunity to plan a healthy lifestyle and consider giving up smoking. A free help line number is printed at the end of this booklet.

Drinking Alcohol

Whilst alcohol in moderation within government guidelines is acceptable it is advisable you reduce the amount you drink if excessive. Information websites on alcohol awareness is printed at the back of this booklet.

Sexual Activity

You can resume normal sexual activity as soon as you feel able.

Starting a family

It is advisable not to start a family until you have had confirmation that the AVM has been obliterated. This is because pregnancy poses a small increased risk of bleeding from the AVM. If you need staged treatment there is also a small increased risk of bleeding in a partially treated AVM.

Once you do start a family, your obstetrician can contact your team at the Walton Centre for advice.
**Sport and swimming**

Most sports can be resumed gradually once you have recovered and the puncture site in your groin is healed; usually after 2 weeks.

It is best to avoid extreme and contact sport until you have had your angiogram.

**Hair Washing and hair dyeing**

You can wash your hair as soon as you feel up to it. The coils will not be affected by dyeing or perming your hair.

**Dental Treatment**

Dental treatment is safe after treatment.
ADVICE FOR CARING FOR PUNCTURE SITE TO GROIN/WRIST POST OPERATIVELY.

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/hand.
• 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.
Can be found on final page
Going home information

Name
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Consultant.............................................................................................................
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Date and type of treatment.................................................................................

Medications:

Appointments:

(To be completed by specialist nurse on discharge)
Walton Centre Contact Details

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

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

For information regarding appointments or DVLA contact your Consultant’s secretary.
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: 0300 790 6806
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: 0345 606 0265
www.awp.gov.uk

NHS Free smoking helpline:
0300 123 1044 (England)
0800 085 2219 (Wales)
www.smokefree.nhs.uk

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