

Arteriovenous malformations (AVM) and their treatment

Information for patients



This leaflet will help to explain what venous malformations are and their treatment; once you have read the leaflet, if you have any questions please do not hesitate to contact the clinical nurse specialist team via the numbers on page 10.

What is an arteriovenous malformation (AVM)?

AVMs occur when blood flows directly from an artery into a vein instead of passing through capillaries. AVMs are often present at birth and may grow in the brain, neck, and spine. Peripheral AVMs are found anywhere on the body including internal organs such as the kidneys, intestines, and lungs. They can show rapid growth over a relatively short period of time during childhood or adulthood. However, at certain times, when the body's hormone levels increase, such as in puberty and pregnancy, they can grow more quickly. This can also be as a result of clotting, infection and trauma. They are one of the rare types of vascular anomaly.

What is a vascular anomaly?

Vascular anomalies or vascular malformations are general terms used to describe an abnormal cluster of vessels. They can come in a number of forms.

Venous malformations. These often have a slow flow of blood running through them.

Arterio-venous malformations. These often have a higher flow of blood running through them.

Lymphatic malformations. These contain a clear fluid rather than blood; venous malformations tend to be very slow flow.

Sometimes there can be a combination of the above.

In this information booklet we will be looking at peripheral arteriovenous malformations (AVMs)

Are they harmful?

AVMs are benign. They are not a tumour or cancer, and whilst some people have extensive problems affecting several areas of their body, they cannot spread to other areas of the body.

Patients who have AVMs may experience the following symptoms:

- Swelling: This is often a soft lump that can appear on any part of the body; the swelling can increase and decrease at different times.
- Pain: This can be mild to severe depending on the size and location of the malformation • Skin discolouration.
- Bleeding.
- Increased swelling and pain caused by clot formation in the malformation.
- Rarely ulceration.

How do we treat AVMs?

You will go through several steps to allow us to make the best decision regarding your care.

Diagnosis

Once we have received a referral from the team looking after you, we will, in the first instance, need to confirm the type of malformation they have and its extent, as this will help us identify the correct course of treatment. You will need to undergo a number of investigations; these may include an ultrasound scan and /or an MRI. Sometimes we may request a biopsy.

MDT (Multidisciplinary Team)

We will often discuss your case with other professionals involved in treating patients with venous malformations to make sure we are taking the best course of action in each case.

Treatment options

Once we have the results from your tests we will invite you to attend an outpatient appointment at which point the interventional radiologists will discuss your treatment options with you.

We may also discuss your case further with colleagues from other disciplines. After discussion we will normally offer the following options.

No treatment

If the malformation is causing you no real problems in terms of living a normal active life and it does not involve sensitive structures, for example your joints, it may be reasonable to leave the malformation alone.

If you decide, after discussion, to take this option then we will normally discharge you from our care. This does not mean you cannot be re-referred if your symptoms increase.

Interventional treatment

If your malformation is causing significant problems and it is agreed that interventional treatment would be your best option, we will place you on our waiting list for treatment. It is important that you understand that the treatments we offer are for symptom control; we cannot cure malformations at present.

Symptom diary

In the interim between referral and treatment we may give you a diary to allow you to log the severity and location of pain and swelling, as well as other problems you may have related to your malformation. If you are given a diary please remember to bring it with you on your treatment date or when you attend clinic.

What does the treatment involve?

This depends on the type of malformation you have.

In this information booklet we will be looking at peripheral arteriovenous malformations (AVMs) also known as high flow malformations. Normally, patients with an AVM are admitted onto a ward as they will need a general anaesthetic and often need close observation following their procedure.

On arrival to the ward you will be clerked in by the ward team. They will put you into a hospital gown, they may also insert a cannula (plastic tube) into your arm to administer drugs and fluids if needed. When we are ready to carry out the procedure we will call the ward to let them know. Once in Radiology Theatres the consultant interventional radiologist performing the procedure will confirm your consent to undergo the procedure and answer any further questions you may have.

Arteriovenous malformations (AVMs) or high flow malformations are treated somewhat differently to venous or lymphatic malformations. Due to their high flow nature it is preferable to embolise (block off) the arteries involved in the malformation. This is done by inserting a fine tube called a catheter into the vessels in the malformation. These vessels are then blocked using different agents as below.

Coils

The coils we insert are like small springs, they are made of platinum or stainless steel

Onyx

This agent forms a solid but spongy cast in the malformation. It is injected by the use of a catheter. It forms a permanent cast in the malformation. The cast can sometimes be removed surgically if needed.

Other treatment options

Absolute alcohol sclerotherapy

This agent is injected into the malformation, but instead of embolising the malformation it causes clots inside the vessels. This can take a while to take effect, thus the radiologist performing the procedure may insert a small balloon in the veins or arteries to block blood flow in or out of the malformation and keep the drug in place while it works.

Surgery

Surgical resection of an AVM is often difficult and recurrence of the AVM is common with incomplete resection. Therefore, only surgically resectable lesions should be selected for the surgical therapy. Often preoperative embolisation with coils for example may be helpful prior to surgical intervention, due to the increased risk of bleeding associated with such anomalies.

Embolisation and sclerotherapy of an AVM can take a few hours to complete. After treatment you will normally be recovered in our recovery area and then go back to your ward.

Embolisation of an AVM is a safe and effective procedure, but as with any medical procedure complications can arise.

Swelling and pain will occur after the procedure. The swelling and pain should generally settle down after a few weeks; during this time simple analgesia such as paracetamol and/or ibuprofen can be used to control the pain. We will contact you to make sure the pain and swelling after the procedure is not excessive.

If the malformation is close to, or just under the skin, there is a risk of skin blistering or ulceration, and rarely skin loss. Most ulcers will heal of their own accord or may require simple bandaging. However sometimes a skin graft may be required to achieve healing of the skin. Skin loss and ulceration can occur if embolisation of the malformation causes blood flow to be reduced to surrounding or other areas of the body.

Bleeding, swelling and bruising under the skin can be a risk due to the fact we are inserting a catheter into your artery or vein. When we remove the catheter we will press on the area for 10 minutes or so to close the puncture site and prevent bleeding, swelling and bruising.

Nerve damage can occur if the malformation is close to a nerve. This may be in the form of a feeling of numbness, tingling and pins and needles and is usually temporary. However, the nerve may be heavily bruised causing longer term symptoms involving both altered sensation and reduced muscle function, this can be temporary or permanent.

There is always a small risk of bleeding and infection as with any procedure involving needle insertion. Risks are minimised by using image guidance to place the needle in the correct position and by using a sterile technique.

Sclerotherapy causes blood clots within the malformation, rarely the clots can extend into the normal veins resulting in deep vein thrombosis (DVT). If you experience generalised swelling of the whole treated limb or part of a limb such as your calf for example this could be a DVT. You should contact us or your GP immediately to determine if this is the case. If a DVT is confirmed you would normally need to have treatment with anticoagulants (blood thinning drugs) for several months

Other risks

Radiation

Sometimes we use X-ray to visualise the blood vessels during the procedure. Radiation doses for the procedure are generally accepted to be low, though occasionally higher doses are required if the procedure is long or demanding.

Compartment syndrome

Sometimes if the malformation is located in a certain area of the body swelling post procedure may cause a condition called compartment syndrome. This is caused when swelling occurs in an area where there is not much room for the swelling to take place without impacting on other structures in the body, the forearm for example. We will often arrange for you to take a small dose of steroids before and after your treatment to avoid this.

Follow up

Before you commence treatment we will ask you which is the best method for you to be followed up.

We have three methods

- **By telephone:** We will take the best contact number for yourself.
- **By email:** We will take the best contact email for yourself.
- **By virtual clinic:** We can talk to you via a private and secure video link. Again we will need your email to arrange a convenient time to talk.

We will contact you one week and then eight weeks after your procedure to see how you are recovering.

At one week we will ask a number of questions which will enable us to establish how you have been after the treatment and make sure you are not having any problems post procedure or suffering from any complications.

At eight weeks we will discuss if your symptoms have improved or not. We will use this information to determine the next best course of action for you; this is normally either further treatment or a clinic appointment.

If you have any questions or concerns in the meantime please contact:

Clinical Nurse Specialists,
Interventional Radiology & Vascular Anomalies
Leeds Teaching Hospitals (09:00-17:00)

Tel: 0113 392 0930 or 0113 392 0931 (Office)

Secretary

Tel: 0113 392 2860

Email: leedsth-tr.vascularmalformations@nhs.net

Please note if you are feeling unwell or unable to contact us regarding any urgent concerns or complications please attend your local GP Surgery, local walk in centre or your local Accident and Emergency Department if appropriate.



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