

Treating a kidney angiomyolipoma (AML) (a non-cancerous tumour) by blocking its blood

Radiology Department

Information for Patients

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Introduction

If you are an outpatient please read your appointment letter carefully. Check which hospital you need to go to.

Please read all of this leaflet. It tells you about your procedure. It has important information and instructions.

What is a kidney angiomyolipoma (kidney AML)?

You say angiomyolipoma like this: ann-gee-oh-my-oh-ly-poh-ma

A kidney angiomyolipoma (AML) is a **non-cancerous lump in the kidney**. It is made up of **fat, blood vessels, and muscle**. A non-cancerous tumour does not spread to other parts of the body.

- Less than 3 in 100 people get a kidney AML.
- Women are 4 times more likely than men to get a kidney AML.
- People who were born with tuberous sclerosis (a rare genetic condition) are more likely to get a kidney AML than people who do not have it.

What symptoms can kidney AMLs cause?

Small AMLs (less than 4cm) do not usually cause symptoms.

Bigger AMLs (more than 4cm) are more likely to cause symptoms. These can be mild or very serious.

The symptoms can include:

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- Bleeding into the tummy (abdomen) and pelvis, which can be serious or life threatening
- New pain in the back or sides of the tummy (abdomen)
- Blood in your pee (urine). You may see it, or it may only show up on a urine test.
- Weight loss
- High blood pressure (hypertension)
- Feeling sick or being sick (nausea and vomiting)

How can a kidney AML be treated?

Your urologist or medical doctor has probably talked to you about the options. The options include:

- **Blocking the blood supply (also called embolisation).** A doctor who specialises in X-ray guided treatments (an interventional radiologist) injects a special material to block the blood supply to the AML. The blood supply to the rest of the kidney is not affected.
- **Heat treatment or freezing (thermoablation).** A needle-like probe is placed directly into the AML. The tumour is either heated to a high temperature or cooled to below freezing. This destroys the AML but does not damage the rest of the kidney.
- **An operation (surgery).** A doctor who specialises in kidneys and bladders (urologist) takes out the AML and some or all of the kidney. How much is removed depends on the size of the AML, where it is in the kidney and how well your kidneys are working.
- **Do nothing.** If the AML is smaller than 4cm and not causing you problems, the option is for you to have either CT scans or MRI scans every 6 months to a year to check for changes.

Embolisation is the option often used when an AML is causing symptoms or at risk of bleeding..

What are the potential benefits of embolisation?

The benefits include:

- you usually stay in hospital for 1 night only
- most people can return to work within 5 to 7 days
- it lowers the risk of bleeding from your AML
- it keeps the rest of the kidney undamaged.
- studies show embolisation can control the growth of an AML for at least 5 to 10 years

Asking for your permission (consent)

The doctor who referred you should have talked to you about why you need this procedure and any other options.

You have been referred to a doctor who specialises in imaging and X-ray treatments (a radiologist). They will check that you understand why the procedure is being done, the potential risks and the chances of success. You will sign a consent form to confirm this. This may be on an iPad or a paper form. **You should feel that you know enough before you sign the consent form.**

If after talking to the hospital doctor or radiologist you do not want to have the procedure then you can decide to say no. We will talk to you about your options.

If the radiologist feels that your condition has changed they will talk to you about if the procedure is still needed. They may ask for the doctor who referred you to review your condition.

Important information about blood thinning medicines:

If you are taking medicine that thins the blood (anticoagulants or antiplatelets) you may need to stop taking it. Or, you may need to take a different one for a few days.

Please call the radiology department for advice as soon as possible. The phone number to call is on your appointment letter. It is also at the end of this leaflet. We will ask you what blood thinning medicine you are taking, how much you take (the dose), and what you are taking it for.

Common examples of these drugs include aspirin, warfarin, clopidogrel (Plavix®), apixiban (Eliquis), rivaroxaban (Xarelto), ticagrelor (Brilinta), dalteparin, edoxaban and heparin.

You may have already been given instructions on blood thinners by the doctor who referred you for this procedure. Please still call the radiology department so we can check this.

Important information before you have X-rays or X-ray contrast:

The contrast liquid used in your procedure has iodine in it. Your kidneys remove iodine from your body. It comes out in your pee (urine). If you have kidney dialysis, this will remove the iodine.

Please tell the X-ray staff when you arrive if:

- **you are allergic to iodine or rubber (latex)**, have any other allergies or have asthma.
- **you have had a reaction in the past to a contrast liquid injected into a vein (intravenous contrast)**. This is the dye used for kidney X-rays, CT scanning and X-rays of your heart and blood vessels.
- **you are on kidney dialysis or have any problems with your kidneys.**
- **you have diabetes.**
- **there is any chance that you may be pregnant.**

Some patients get a warm feeling and a metallic taste when the injection is given. Some may feel sick. If you do get these feelings they usually last about 1 minute. Some patients will also have the feeling that they are passing urine but they are not actually doing so. This is also normal.

How do I get ready for the procedure?

You may need to have a CT scan of your tummy. This is to help plan the embolisation procedure. We will tell you if you need a CT scan.

You will have a pre-assessment appointment. This is to make sure that everything is suitable and ready for the procedure. We may do some of this in a phone call to you.

The pre-assessment appointment may include:

- Talking about the procedure with an interventional radiology doctor or nurse.
- Talking about your medical history and any medications you take.
- A physical exam. This involves checking your tummy, heart rate and blood pressure. If your pre-assessment appointment is over the phone we will do your physical exam when you come for the procedure.
- Swabs to check for infections. Blood tests to check for your risk of bleeding. If you need either of these and your pre-assessment appointment is by phone we will send you the forms and instructions on how to get these done.
- Signing a consent form for you to give permission to have the procedure.

Can I eat and drink before the procedure?

- Do not eat any solid food after 12 midnight, the night before the procedure.
- You can have water on the morning of the procedure.

How long will the embolisation take?

The procedure usually takes about 2 to 3 hours.

Who will be doing the procedure?

- a doctor who specialises in imaging and X-ray treatments (an interventional radiologist) will do the procedure.
- someone trained to take X-ray pictures (a radiographer) will control the X-ray machine.
- a radiology nurse and healthcare assistant will help the radiologist and care for you.
- we are a teaching hospital, so a student may also be in the room. If you do not want this, you can ask that a student is not in the room when you have your procedure.

How long will I be in the hospital?

Most patients are in the hospital for about 1 day and night.

You will come to the hospital on the day of the procedure.

You can expect to go home in the late morning or early afternoon the day after the procedure.

What happens during the procedure?

- It is usually done in a special X-ray room (interventional X-ray) in the Radiology Department.

Getting ready

- We will take you to a private room or cubicle. We will ask you to take off some of your clothes and put on a hospital gown.
- We will put a thin tube (cannula) into a vein in your arm or the back of your hand. This is so we can give you medicines if needed. This may include some sedation to help you feel more relaxed. The sedative will make you feel drowsy but not make you to sleep. We can also give you a pain killer if you need it.
- We will take you into the special X-ray room.

In the X-ray room

- You will lie down flat on your back on the X-ray table.
- We put a blood pressure cuff (strap) on your arm and a small peg on your finger. These will all be attached to a monitoring machine. This is to check your blood pressure, your heart rate and your heart health.
- We will keep everything clean (sterile). We clean your skin with antiseptic. This may feel cold. We cover some of your body with sterile sheets.

Doing the procedure

- We inject some local anaesthetic into the skin and deeper tissues over the blood vessels in your groin or wrist. This may sting to start with. This soon wears off and the skin and deeper tissues should then feel numb. Please tell us if the procedure does become uncomfortable.
- We will put a small needle will be put into an artery in your groin or wrist.
- We will then put a thin tube (catheter) into the artery. We push it slowly to the kidney.
- We will inject a colourless liquid called contrast through the catheter. This shows up on X-rays. This is so we can see the arteries and the AML in your kidney.
- When we are sure we are in the right place, we inject tiny plastic particles into the artery supplying the AML. These particles will block the blood supply to the AML.

Finishing the procedure

- At the end of the procedure, we take out the catheter in your groin or wrist. We will press firmly on the skin entry point to stop bleeding and reduce bruising.
 - If we put the catheter in at your groin, we may use closure device to help seal the artery.
 - If we put the catheter in at your wrist, we may put a vascular compression band on your wrist.
- We will tell you about this at the time.

What happens after the procedure?

- We will take you to the radiology recovery room. Nurses will do routine checks, such as taking your pulse and blood pressure. This is to make sure there are no problems. They will also look at the skin entry point to make sure there is no bleeding from it.
- You will then be taken back to your ward. Nurses will continue to do routine checks.
- You will need to stay in bed for 2 to 6 hours after the procedure. You will be told at the end of the procedure how long you must rest in bed. After that time, you can get out of bed but you should take it easy.
- Some patients have moderate to severe pain in back or the side of the tummy after the procedure. Some patients feel sick. Tell the staff looking after you if you have any pain or feel sick. They can give your medicine through your cannula if needed. The pain usually gets better over the next 2 days.
- Some patients get very strong pain after the procedure. If this happens you will be given pain relief. It is called patient controlled analgesia (PCA). This lets you press a button to give yourself extra pain medicine safely when you need it.
- Some patients will need to stay in the hospital overnight. This will be decided once your procedure is done.

How do I get the results?

You will not get the results straight away.

The interventional radiologist will look at your X-ray pictures again. We will send your results to the consultant or GP who referred you for this procedure.

After your procedure we will tell you who the results will go to and how to get your results.

What happens when I go home?

You may have 'flu-like' symptoms for 5 to 7 days after the procedure.

Symptoms can include:

- mild raised temperature (fever)
- feeling sick
- aches and pains
- tiredness

Rest and taking the prescribed painkillers or your usual painkillers usually helps. Most people are able to go back to doing light work within 5 to 7 days.

Do not drive for 48 hours (2 days) after the procedure. You will need someone to drive you home.

If you had sedation please follow the advice below.

For 12 hours:

- you must have another adult with you

For 24 hours:

- do not drive a car, ride a bicycle or climb ladders
- do not drink alcohol.
- do not use any machinery or do anything that needs skill or judgement.
- do not make important decisions or sign any documents.
- do not return to work until after 24 hours **or until you are well enough**
- do not take any hard exercise or heavy lifting.

When can I go back to work?

You should be able to go back to your usual work or activity within 1 week.

What are the risks from exposure to radiation in this procedure?

The main risk from exposure to X-rays is a higher risk of getting a cancer in the future. This risk is thought to be very small.

We are all exposed to natural background radiation every day of our lives. This comes from the sun, the food we eat, and the ground. Each test that uses X-rays gives a dose on top of this natural background radiation.

The risks of radiation are slightly higher for an unborn child. We must ask all patients age 10 to 15 years registered female and all patients aged 16 to 55 years about their periods and/or possibility of being pregnant.

The benefits of having this procedure are likely to outweigh any possible risks. The risks of not having the procedure could be greater. We try to keep your exposure to X-rays as low as possible.

Are there any risks?

As with any procedure there is a risk of complications. Below are the most common risks and complications. The chance of these happening is different for each person. We will talk to you about your risks before you sign the consent form.

- **Bleeding** from the puncture site where the small tube is inserted. If bleeding happens, it is usually easy to stop. The risk of a larger amount of bleeding happening is less than 1 in 100 people (1%).



- **Allergic reaction** to a medicine used during the procedure.
- **Reaction to contrast liquid.** Some patients may be allergic to the contrast liquid. You could get symptoms such as feeling or being sick (nausea or vomiting), or a rash. Any side effects usually happen within 20 minutes. If you get any of these symptoms at the hospital, tell the doctor, nurse or other staff looking after you. If you start to get symptoms at home you should contact your GP or call 111
- **Infection** in the area treated. This can cause an abscess or fluid collection. This could need another procedure to put a drainage tube in your kidney to help with the healing. This happens in less than 3 in 100 people.
- **Kidney failure.** This can happen if the AML is so big that embolisation damages the blood flow to the whole kidney. This can cause the kidney to stop working. If your other kidney works well, then this should not cause problems. If your other kidney does not work well there is a risk you could need dialysis treatment.
- **Having the kidney taken out (nephrectomy).** There is a risk of damage to the kidney that would need an operation to fix. The risk of needing to have the kidney taken out (nephrectomy) is less than 1 in 100 people (1%).

What if I need to talk to someone?

If you have any questions or concerns, or cannot make the appointment:

Please call the Radiology department on **0116 258 8765** and select **option 7**. Monday to Friday 9am to 5pm, but not on bank holidays.



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Previous reference:

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