

# **Information for adults considering screening for brain aneurysm**

## What is the aim of this booklet?

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This booklet is for adults thinking about having a test to look for an aneurysm in the brain.

There is uncertainty about whether screening for brain aneurysms is helpful. There is a lot of information for you to consider before making a decision about screening. Because the amount of information can be difficult to take in during a clinic appointment, we would like you to consider the information in this leaflet before making a decision. **There is no rush**, so take time to discuss the issues with your general practitioner (GP) or your family, if you wish. For more information about screening, visit **NHS Screening Inform**:

[www.nhsinform.scot/healthy-living/screening](http://www.nhsinform.scot/healthy-living/screening)

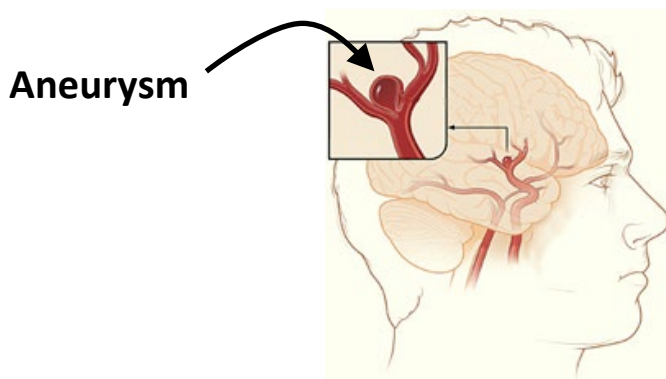


**When you have made a decision**, please follow the instructions about what to do next, which are described at the end of this booklet.

## What is a brain aneurysm?

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A **brain aneurysm** is a balloon-like swelling of an artery, which is a type of blood vessel, inside the skull. Aneurysms vary in size from a few millimetres to a few centimetres.



**Aneurysms develop during life. Most brain aneurysms never cause symptoms and people are unaware they have them.** Occasionally, aneurysms burst (rupture) and cause bleeding (haemorrhage) in or around the brain. This bleeding can be fatal or disabling. Sometimes aneurysms do not burst, but cause symptoms by pressing on nearby structures.

## **How common are brain aneurysms?**

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Roughly 3% of adults in the UK have a brain aneurysm. That means that these ‘unruptured’ brain aneurysms affect about 3,000 people in every 100,000. Yet only about 8 of these 100,000 adults will have a bleed from an aneurysm in any one year.

Some of these 8 bleeds may have arisen amongst the 3,000 people with unruptured brain aneurysms, but we think that some do not because aneurysms sometimes develop rapidly and then bleed.

**Most people who develop aneurysms in their brain never experience any problems throughout their lives.**

## What makes bleeding from a brain aneurysm more likely?

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You can change things that make you more likely to have a bleed from a brain aneurysm. These **modifiable factors** are:

- Smoking **cigarettes**
- Having **high blood pressure**
- Drinking **too much alcohol** (that is regularly exceeding 2-3 units of alcohol daily for women or 3-4 units of alcohol daily for men).

These modifiable factors account for most of the risk of bleeding from brain aneurysms in the population. The same factors put people at risk of cancer, heart and liver disease & so on.

**We think that for most people, stopping smoking, controlling high blood pressure, and cutting back if you drink too much alcohol, are more beneficial than screening.**

We do not recommend screening for brain aneurysms because people smoke, drink too much, or have high blood pressure. But we do consider screening if brain aneurysms definitely run in your family.

### **Do brain aneurysms run in your family?**

Brain aneurysms may run in families. If brain aneurysms run in your family, you are more at risk of having a brain aneurysm than the average 3%. Your risk depends on **how many relatives** have been affected by bleeding from a brain aneurysm, and **how closely related** to you they are.

If you think you have a family history of brain aneurysms, it is **essential for you to work out:**

1. That doctors were **certain** that a relative of yours had a brain bleed (subarachnoid or cerebral haemorrhage) from a brain aneurysm.

2. How many of each type of 'close relative' has been affected by a bleed from a brain aneurysm. There are two types of close relative:

- **First-degree:** sister, brother, mother, father, son, or daughter
- **Second-degree:** half-brother, half-sister, aunt, uncle, grandparent, grandchild, nephew, or niece

**If you have two or more affected first-degree relatives**, your risk of having a brain aneurysm is 8% (8 in 100), which is higher than average (3 in 100). We do not know the exact risk of you having a bleed from an aneurysm in your lifetime, but it seems higher the more first-degree relatives you have affected.

Some other rare inherited conditions, such as polycystic kidney disease, are also associated with a higher risk of having a brain aneurysm.

- **We consider screening** for people with **two or more first-degree relatives** affected by a bleed from a brain aneurysm, and the identical twins of people with a brain aneurysm.
- **We also consider screening** people who have one first-degree relative and one or more second-degree relatives with a bleed from a brain aneurysm.
- **We do not recommend screening** for people with weaker family histories.



## What is a screening test?

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Screening is a process of identifying people who may be at a higher risk of a disease or condition than average, and then trying to reduce that risk. There is uncertainty about whether many screening tests are helpful. You should bear in mind some of the requirements of the perfect screening test, which are:

- The screening test must be readily available, inexpensive, safe and agreeable to the people it will be used on
- There should be an agreed policy, based on good evidence, about which people to refer from the screening programme for a test
- The risk marker (an aneurysm) should be a reliable indicator that a disease will develop
- The risk marker (an aneurysm) should also be able to identify who will develop disease (brain haemorrhage) and who will not
- The treatment for the risk marker (aneurysm) should be effective
- Screening should do more good than harm.

## What screening tests do we use?

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Two different screening tests are available, which image blood vessels looking for aneurysms:

- A Computerised Tomography Angiogram (CTA). This involves you lying flat in a CT scanner, which is not claustrophobic, for five minutes and having an injection into a vein in your arm. A CTA does involve radiation exposure, which is equivalent to being exposed to about 300 days of exposure to natural background radiation. There is a slight risk (approximately 1 in 5,000) that exposure to radiation from a CTA scan would cause a radiation-induced cancer.
- A Magnetic Resonance Angiogram (MRA) does not involve radiation, but some people become claustrophobic in the scanner, and people with some metal implants cannot be scanned with MRA.

## What are the advantages of screening?

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1. A normal test **reassures** you that you do not appear to have a brain aneurysm now.
2. If an aneurysm is found, it **provides an opportunity to treat it before it ruptures**.
3. If treatment of an aneurysm found by screening is successful, you may have been **protected from it rupturing** in the future.

## What are the disadvantages of screening?

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1. **Screening tests can miss aneurysms.**  
Aneurysms that are missed tend to be very small, and these are the least likely to bleed and the most difficult to treat.
2. The **screening tests carry risks**. CTA involves radiation exposure. CTA and MRA may reveal other unexpected incidental abnormalities, which may cause anxiety and dilemmas about whether to treat them.
3. Because most unruptured aneurysms never cause a problem in someone's lifetime,

**identifying such aneurysms may cause unnecessary alarm and concern.**

4. Some aneurysms discovered by screening may have a very low estimated risk of rupture, which is likely to be less than the risks of treatment. We tend not to treat these aneurysms, which can leave you feeling **anxious**.
5. Screening may identify an aneurysm that **cannot be treated**.
6. **Treating aneurysms can be risky**, and may not block off the aneurysm completely.
7. Aneurysms can have implications for your **driving licence and travel or life insurance**.
8. In summary, **it is unclear whether identifying unruptured aneurysms by screening leads to more good than harm**.

## What if the screening test is normal?

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Although a normal screening test is reassuring, **it is not a guarantee** because aneurysms develop throughout life. We do not know whether screening should be repeated, or how often. A study that used complex calculations to simulate the real world estimated that the optimal strategy for screening adults with two or more affected first degree relatives is to **screen them with MRA at 7-yearly intervals between 20 to 80 years of age.**

## What if screening finds a brain aneurysm?

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Finding an aneurysm does not mean that treatment is either desirable or possible. We would send you an appointment for our clinic to discuss this further. You may need more tests to give us further information about the aneurysm. It is very important that we discuss with you the **uncertainty about whether treating unruptured aneurysms is the right thing to do.** At your appointment, **we will**

**discuss** the pros and cons of treatment, including:

- The estimated **risk of the aneurysm bleeding**. This is only known in the short term. It depends on the location, size and shape of the aneurysm and your age.
- The **treatments** available. Traditionally, aneurysms have been treated with **surgery**, which involves a brain operation. Increasingly, we are treating aneurysms by **endovascular** means, which use small devices (coils, stents, or balloons) introduced via a fine tube in an artery in the groin (this does not involve a brain operation). Both treatments are done under general anaesthetic.
- The **risks of treatment**, which are affected by the aneurysm's characteristics, your age, and your general health.

## **About the aneurysm screening clinic for NHS Lothian patients**

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This clinic runs on a monthly basis in outpatients at the Department of Clinical Neurosciences, Bioquater, Little France, Edinburgh. Those involved in the clinic include:

- **Neuroradiologists**
- **Neuroradiology Fellow**
- **Neurosurgeon**
- **Clinical nurse specialist**

**Neurologists** see patients in their own clinics.

If you do come to the clinic, please bring as much information as you can about any relatives affected by brain aneurysms, and a list of the questions you want to ask.

We will not expect you to make up your mind at the time of your appointment, and are happy for you to go away and think it over.

If you live outside NHS Lothian your GP will refer you to your local Neurology department.

### **Choice about whether to have screening**

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Decide how important the pros and cons of brain aneurysm screening are for you. Take some time to work out whether or not you are sure you want screening. Follow the advice on the last page about what to do next.



## Other sources of information

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Two very useful sources of information about screening in general are:

- **Making sense of screening**, by Sense About Science:

[www.senseaboutscience.org](http://www.senseaboutscience.org)



- NHS Inform:

[www.nhsinform.scot/healthy-living/screening](http://www.nhsinform.scot/healthy-living/screening)



# Notes about your family history/Questions for Clinic

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## After reading this leaflet...

### If you know you **do not** want screening...

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Keep this leaflet in a safe place for future reference.

### If you are unsure, or you **do** want screening...

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If your GP has already referred you to our aneurysm screening clinic we will be in touch in due course.

If your GP has not referred you to our aneurysm screening clinic and you live within NHS Lothian please ask them to refer you to the Neurointervention service, Dr RJ Davenport or Prof RA Salman at the Department of Clinical Neurosciences, RHCYP/DCN, Bio Quarter, Little France, Edinburgh, EH16 4TJ.

If live out with the Lothian area and your GP has referred to your local Neurology department please contact your GP if your require an update