

## Information for adults considering screening for brain aneurysm

### What is the aim for this leaflet?

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

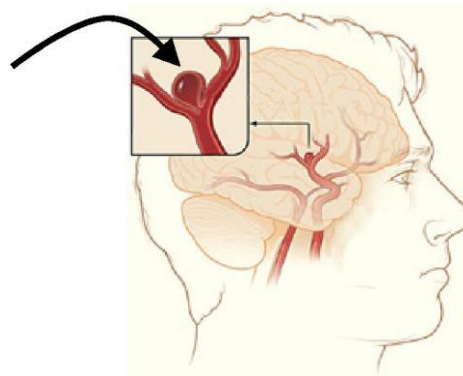
There is uncertainty about whether screening for brain aneurysms is helpful. There is a lot of information for you to consider before making a decision about screening. Because the amount of information can be difficult to take in during a clinic appointment, we would like you to consider the information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

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

### What is a brain aneurysm?

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

Aneurysm



**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?**

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 eight of these 100,000 adults will have a bleed from an aneurysm in any one year.

Some of these eight 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?**

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, and 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, and **how many 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 the 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. These 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 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 brain aneurysm.**
- **We do not recommend screening people with weaker family histories**

### **What is a screening test?**

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 program for a test.
- 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 test do we use?**

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

- We usually request a CT 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.
- An MR angiogram (MRA) is an alternative. 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?**

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?**

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 is the screening test is normal?**

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?**

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.

### **Review of our brain aneurysm screening clinic from 2006-2009**

- 77 adults had a family history of brain aneurysms.
- 35 adults had two or more affected first-degree relatives. We screened 29, six of whom had an aneurysm.
- 21 adults had one affected first-degree and at least one second-degree. We screened 15. Two had an aneurysm.
- 21 adults had just one affected first-degree relative. We screened five, one of whom had an aneurysm.
- Of the nine patients with aneurysms, four had treatment
- The paper is published in the JNNP.

### **About the aneurysm screening clinic**

This clinic runs on a monthly basis in outpatients at the Department of Clinical Neurosciences, Western General Hospital, Edinburgh. Those involved in the clinic include:

- Neurologists (Dr Richard Davenport and Dr Rustam Al-Shahi Salman)
- Neuroradiologists (Dr Phil White, Dr Robin Sellar, and Dr Peter Keston)
- Neurosurgeon (Mr Ioannis Fouyas)
- Nurse specialist (Ms Karen Briggs)

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.

### **Making your choice about screening**

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**

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)
- The NHS Screening Portal [www.screening.nhs.uk](http://www.screening.nhs.uk)

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

- Keep this leaflet in a safe place for future reference

#### **AFTER READING THIS LEAFLET...**

**If you are unsure, or you do want screening and your GP has already**

referred you to our aneurysm screening clinic:

- Call 0131 537 3330, and give your name, date of birth and telephone number
- Mention that you have been referred for aneurysm screening and ask for an appointment to be sent to you.

If your GP has not referred you to our aneurysm screening clinic, please ask them to refer you to Dr RJ Davenport, or Dr R Al-Shahi Salman, or Dr P White at the Department of Clinical Neurosciences, Western General Hospital, Edinburgh.