

**Note: This is a guide for your information and consideration and does not constitute medical advice. HBA Support is a not-for-profit organisation providing information based on our experiences. For any medical concerns or questions, always consult your GP or a qualified healthcare professional.**

# *Understanding Familial Brain Aneurysms*

Most brain aneurysms occur sporadically, meaning randomly with no pattern, and are not hereditary. However, sometimes patterns can occur in families.

When two or more first-degree relatives (such as a parent, child, or sibling) have proven brain aneurysms that indicate a hereditary pattern, people can be given the diagnosis of 'familial aneurysm syndrome'. Once diagnosed, family members may be referred for further investigations and screenings. In the medical community, these are often referred to as familial aneurysms.

## *What Should You Do If You Suspect a Family Pattern?*

If you have a strong family history of brain aneurysms, or suspect you may be at risk, there are several proactive steps you can take:

### **1. Consult Your GP:**

Your first step is to visit your GP and discuss your family history with them and your worries. They can help assess your risk and provide guidance on possible next steps. This could include a referral on to a neurosurgeon or neuro interventional specialists to discuss screening via a brain scan. They could also refer you to a genetic counsellor too who can help you look at your family history, and help you explore whether screening is right for you. Some patients find it useful to take relevant information with them, including a diagram or a note of who has been affected in your family. For more information on hereditary brain aneurysms, visit <https://www.hbasupport.org/information>.

### **2. Understand Guidelines:**

According to NICE guidelines, familial aneurysms occur when two or more first-degree relatives have had a brain hemorrhage from an aneurysm or have diagnosed unruptured aneurysm/s. In these cases, screening may be offered through a brain scan. However, even if you don't meet these criteria, it's still important to talk to your GP if you have concerns. If you are referred to a neurosurgeon or neuro vascular specialist, they will be able to offer advice tailored to your personal situation and family history and guide you on appropriate next steps.

### **3. Screening Options.**

There is no blood test available to see if you have the hereditary condition yet, but we are hopeful that once researchers have found the genetic cause there will be. Until then, screening is done through brain scans. An MRA (Magnetic Resonance Angiography) or MRI (Magnetic Resonance Imaging) scan may be offered. These scans can help detect aneurysms early, offering a chance to treat them before they become problematic.

### **4. Consider What's Right for You:**

Screening for brain aneurysms is a personal choice. Some people who are offered screening choose not to undergo it due to the anxiety it may bring. Often, discussing your risks with specialists, such as genetic counsellors or a neurosurgeon or nurse specialist, can help you make an informed decision.

## **5. Genetic Counselling:**

You may be referred to a genetic counsellor who can help interpret your family history, discuss the likelihood of inherited aneurysms, and guide you on the appropriate screening and preventive measures. They may also refer you to genetic testing to rule out any other genetic conditions which have aneurysm as a symptom, such as Polycystic Kidney Disease or PKD ([Polycystic Kidney Disease \(PKD\) \(pkdcharity.org.uk\)](https://pkdcharity.org.uk)).

### *What if I Am Diagnosed with a Familial Aneurysm?*

If an aneurysm is discovered, the specialist—usually a neurosurgeon or neurovascular specialist—will work with you to determine whether it should be treated, and if so, what treatment is appropriate. Sometimes, a 'watch and wait' approach is suggested, depending on the size and location of the aneurysm. This means regular monitoring through screening to track its size. If no aneurysm is detected, a repeat screening may be recommended in the future.

Decisions regarding screening and treatment depends on your family history, your willingness to be screened, and the advice of your clinician. The choice is personal, and it's always up to you to decide what's best for your situation.

### *Children and Young People*

Thankfully, intracranial or brain aneurysms are extremely rare in children and young people. From what researchers understand, brain aneurysms usually develop in adulthood. Evidence shows brain aneurysms are more common in people over the age of 40.

While we understand parents and family members will be naturally worried about their children or younger members of their family, based on research available, screening on the NHS is generally recommended in young adults, when they are able to make a personal choice. We're aware that some neurosurgeons and neuro specialists have different viewpoints and recommend screening should start at 30 or at 10-5 years younger than the youngest affected relative, whichever comes first.

Because of the lack of a standard recommendation, we always recommend talking to your neuro specialist about your worries and concerns as all family and medical circumstances are different and unique, and their advice will be tailored to you and your family.

### *Where Can I Go for More Information?*

If you have been diagnosed with a hereditary brain aneurysm, HBA Support offers useful information to help you navigate your options. Please take a look at our website (<https://www.hbasupport.org/support>) for further patient guides and information, including advice on speaking to family members who may also be at risk.

Although everyone's journey is different, there are various treatment options available. Discuss the best path forward with your specialist or neurosurgeon. For more information on treatment options, visit the NHS website: [Brain Aneurysm - Treatment - NHS](https://www.nhs.uk/conditions/brain-aneurysm-treatment).

## Useful Resources

- NHS Lothian Guide: For those considering screening, NHS Lothian offers a helpful guide. [https://policyonline.nhslothian.scot/wp-content/uploads/2023/03/Information\\_for\\_adults\\_considering\\_screening\\_for\\_brain\\_aneurysm.pdf](https://policyonline.nhslothian.scot/wp-content/uploads/2023/03/Information_for_adults_considering_screening_for_brain_aneurysm.pdf)
- Additional Support: Explore stories from individuals with similar experiences, FAQs, and further resources at [HBA Support's website](https://hbasupport.org) at hbasupport.org. Email us at [support@hbasupport.org](mailto:support@hbasupport.org) for more information. You can also sign up to our [regular newsletter](#), which can help with up-to-date news and resources.
- Speak to a specialist neuro nurse: [The Brain and Spine Foundation](#) offers a FREE specialist helpline, staffed by experienced neuro nurses. You can call for free on 0808 808 1000 (Monday – Friday, 9am – 4pm).

## Decision-aid for screening:

### Reasons individuals may choose screening:

- The awareness and knowledge of an aneurysm found can enable lifestyle or medical interventions to prevent ruptures, and potentially save your life.
- The reassurance and reduction of anxiety if no aneurysms are found.
- Opportunity to treat an aneurysm now or in the future if a surgery is advised
- Being able to take proactive steps to manage your health and wellbeing and making positive lifestyle choices.
- Taking away the fear of the unknown by confirming a diagnosis, one way or the other.

### Reasons individuals may not choose screening:

- The possibility the screening may miss an aneurysm.
- Identifying such aneurysms may cause ongoing worry and concern.
- Some patients with aneurysms are put on a watch and wait regime. That's where an aneurysm is regularly monitored for growth. If it grows, then treatment options are discussed. Some small aneurysms are too risky to treat straight away due to size and position. This could lead to anxiety.
- There are very small risks associated with the screening process. Very small radiation exposure in CTA scans can slightly increase your chances of developing cancer, although this risk is thought to be very small, (less than 1 in 2,000 or 0.0101% risk [8-9]).
- The possibility of additional but unrelated health findings.