Your Guide to Hereditary Brain Aneurysms

Screening, diagnosis, treatment and beyond

> "If you're concerned about brain aneurysms in your family, this guide provides the clear, accurate information you need."
>
> **Alberto Nania,**
> **Interventional and Diagnostic Neuroradiology Consultant, University Hospital Southampton**

HBA Support

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Contents

> "This guide is what I needed when I was starting my journey. It addresses the real questions and concerns people have, with facts instead of fear"

Rebecca Middleton,
Founder and CEO, HBA Support

About this guide

For patients, by patients, with insights from medical experts

"What do I really need to know right now?" That's the question we asked people who've stood where you are today. Through conversations and surveys, we listened to what patients and families ***wish*** they'd known from day one and built this guide around their answers.

We then partnered with specialists – interventional neuroradiologists, neurosurgeons, specialist neuro nurses, genetic counsellors and health communicators – to ensure every piece of information is **accurate, easy to understand, up-to-date, and truly helpful**.

About HBA Support

HBA Support is the UK charity behind this guide. We were founded in 2021 by Rebecca Middleton, a patient who lost her mother and grandmother to brain aneurysms before being diagnosed and treated for her own. After struggling to find reliable information during her journey, Rebecca created HBA Support to ensure no family would face this alone.

Our approach is simple

We believe in changing the story from fear to hope, and from isolation to community.
We listen to patients, work with medical experts, and create resources that help.
You're not alone in this.

This was the advice our community told us they'd wish they'd heard when they were diagnosed with a hereditary brain aneurysm

"Ask questions and keep asking until you are satisfied they have been answered"

"Do your research, knowledge is power... it's really scary in the beginning but learn"

"Join an aneurysm group, it is very helpful"

"Don't consult 'doctor Google'"

"Remember you had it before it was discovered, don't let it stop you from living your life"

"Seek out others in the same position and ask a lot of questions of medical professionals"

Understanding hereditary brain aneurysms

What is a brain aneurysm?

When a blood vessel wall in the brain becomes weak, it can sometimes bulge outward like a balloon. This is called a **brain aneurysm**. They can be very small (tinier than a grain of rice) or larger (like a grape), and they can appear in different parts of the brain and take different shapes. Every aneurysm is unique.

How common are brain aneurysms?

An estimated **1 in 30 people** has one (approximately **3% of the UK population**). That means that around two million people are living with an unruptured aneurysm today.

Many people live with a brain aneurysm for years without any symptoms and some people never know they have one. Sometimes they are found by accident during scans or tests for something completely unrelated.

What's my risk of developing an aneurysm?

Most aneurysms happen at random and are called sporadic aneurysms, but **some run in families and are called hereditary or familial aneurysms**. You may be at higher risk if close relatives have been diagnosed.

Research indicates that 1 in 8 people who have an aneurysm has the familial or hereditary condition.

- Studies suggest between 2-29 people out of 100 with strong family history may have an unruptured aneurysm*
- This compares with less than 1-9 people out of 100 in the general population
- Family history can increase risk, but the amount varies greatly between families and studies
- Women are 1.6 times more likely to develop aneurysms than men and that risk increases to 2.2 times more likely after the menopause.
- Most aneurysms are found between ages **35 and 60**, but they can happen at any age in adulthood
- **Smoking, high blood pressure**, and some medical conditions can also raise your risk – see page 12

*Estimates vary because most aneurysms cause no symptoms and remain undetected.

> **"Today's advanced imaging lets us detect aneurysms early, and with improved input from surgical subspecialists we're able to offer safer, more effective treatments and the best long-term care options for each patient."**
>
> Mr Samir Matloob,
> Consultant Neurosurgeon

Do aneurysms cause symptoms?

Most don't. Many people live their whole lives with an aneurysm and never know it. In rare cases, a large aneurysm might press on nerves in the brain, causing headaches, eye pain and double vision or vision loss.

What if one ruptures?

This is rare. Out of 1000 people with small aneurysms (under 10mm), about 7 might experience a rupture in any given year, rising to 4 in 100 for people with aneurysms 10mm or larger. Your individual risk depends mostly on the characteristics of any aneurysms you may have (like their size and location) and whether they're hereditary rather than sporadic (don't run in families).

It can happen suddenly – people describe it as "blinding pain" or like being "hit on the head". It's a medical emergency and can cause serious damage. That's why early detection is important, so doctors can assess your risk and offer treatment if needed, before that happens. Preventative care can save lives.

Takeaways

Every person and aneurysm is different

Aneurysms are relatively common in the UK

Ruptures are rare, but serious

Most unruptured aneurysms cause no symptoms

Screening may be an option if you have a strong family history

Most people with unruptured aneurysms live full, active lives

Your care journey

Everyone's path is different but knowing what to expect can help you feel more **confident** and in control. Here's how people often move through the care journey

Step 1: Brain aneurysm discovery

Family history

You've noticed a pattern and would like to speak to your GP.

→ Go to Step 2

OR

Incidental finding

In some cases, an aneurysm may be found that may not be hereditary and instead be picked up during a routine brain scan for another medical reason. You will then be offered specialist support to talk through the findings.

→ Go to Step 5

STEP 2: Talking to your GP about family history

In this appointment you'll talk about your concerns and share your family history. Your GP will decide whether to refer you to a specialist. See page 15 for how to prepare.

Referred to a neuro specialist

→ Go to Step 3

OR

Not referred

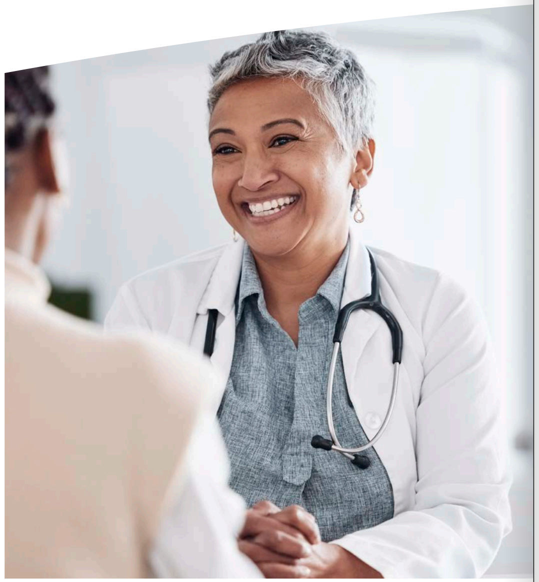
Your GP may say your risk is low.
If you're not satisfied, you can:

Ask for a second opinion

Request private screening

→ Go to Step 4

Ask for a referral to a genetic counsellor
See page 14



STEP 3: Specialist assessment

You'll meet with a specialist (usually a neurosurgeon or specialist nurse) and they'll assess whether screening (a scan to check for aneurysms) is recommended.

You'll usually be offered screening if you have:

- Two or more close relatives (parent, sibling, or child) with brain aneurysms
- An identical twin with a brain aneurysm
- You may also be offered screening if you have one close relative ***plus*** one or more second-degree relatives (e.g. grandparent, aunt/uncle) with aneurysms

Even if you don't meet the exact criteria, the specialist may still offer screening as every case and every family is different. A genetic counsellor can help you to piece together your family history. See page 14 for how to contact a genetic counsellor.

NEXT STEPS

Screening is offered and you choose to go ahead

→ Go to Step 4

OR

Screening is not offered or you choose not to have it

→ Take a look at our lifestyle guidance to take proactive steps on managing your health.

Why choose to screen? (It's your choice)

Screening is optional and every person's situation is unique. Only you will be able to decide the best course for you. Be assured your choice is individual and your choice is valid. You always have the option to revisit later, if you would like to, and talk it over with trained specialists.

BENEFITS	THINGS TO CONSIDER
Some reassurance if no aneurysm is found*	Very small aneurysms can occasionally be missed
Early detection can help you to take action to reduce risk, e.g. stop smoking	Finding one may cause anxiety, even if it doesn't need treatment
Allows time to plan preventative treatment, if needed	Some aneurysms can't be treated due to their size or location

*Remember, if a scan doesn't show an aneurysm, it doesn't guarantee that you won't develop one in the future.

STEP 4: The screening scan

When you go to the appointment, wear comfortable clothing and avoid metal (like jewellery or bra underwires). You can go home straight after and return to normal activities.
Types of scans you may be offered include:

CT Angiogram (CTA)

Uses a small injection of contrast dye in your arm and involves some radiation exposure but is very fast (about 5 minutes).

Magnetic Resonance Angiography (MRA)

Uses magnetic fields (no radiation) but takes longer (30–45 minutes). Isn't suitable for people with some metal implants like some kinds of pacemakers. If you are claustrophobic, let your doctor or nurse know beforehand.

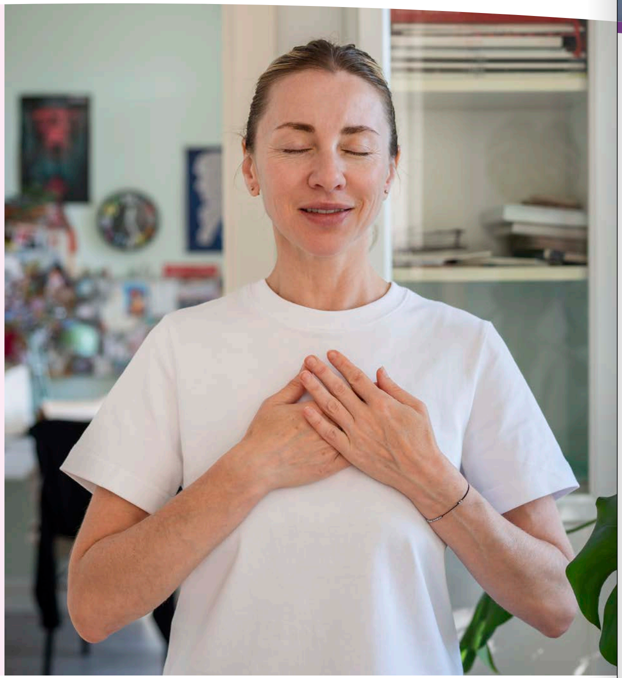
What about genetic screening?

Genetic screening isn't available right now, but the ROAR DNA Study could help us understand more about the genetic links. See page 18 for more information.

→ Go to Step 5

Mental health matters

Screening can bring up difficult emotions. If you're feeling anxious, overwhelmed or unsure, speak to your nurse or GP about support or a referral to mental health services. There are several online resources too that could help you through this journey and worry, for example HBA Support's **Living With Health Anxiety**, available on the resources section of our website.



Important to know

Finding an aneurysm does not mean it will rupture or that you'll need surgery. Many remain small and stable for years – and may never need treatment at all.

STEP 5: Getting your results

If something is found, you'll meet with your specialist to talk through the results (face-to-face, letter or telephone consultation). If your consultation is face-to-face, it can help to bring a friend or family member for support and to help remember what's said.

No aneurysm found	OR	Aneurysm found
You'll get reassurance and advice on keeping your vascular system healthy		Your specialist will explain the size, location, and any signs of risk
You may be offered future screening, depending on your family history and risk		You'll discuss whether monitoring or treatment is recommended
→ Go to Step 7		→ Go to Step 6

STEP 6: Making a treatment plan

If an aneurysm is found, your medical team will talk with you about the best next step. This depends on the aneurysm's size, shape, location, your family history, and your own preferences.

Active Observation

Also called watch and wait or regular monitoring. For many people, **no immediate treatment is needed**. Instead, you'll be closely monitored through regular scans (usually every 1–5 years) and given advice on reducing your risk through lifestyle changes (like managing blood pressure and stopping smoking – see page 12). Watch and wait is often safest for small, stable aneurysms. There's a common misconception that it's 'doing nothing', but it's an active, tried and tested treatment plan.

→ Go to Step 7

OR

Treatment

Treatment may be recommended if the aneurysm is larger, growing, in a high-risk location, or if there are other risk factors to consider. You'll meet with an interventional neuroradiologist or neurosurgeon to discuss options, which may include:

Endovascular treatments

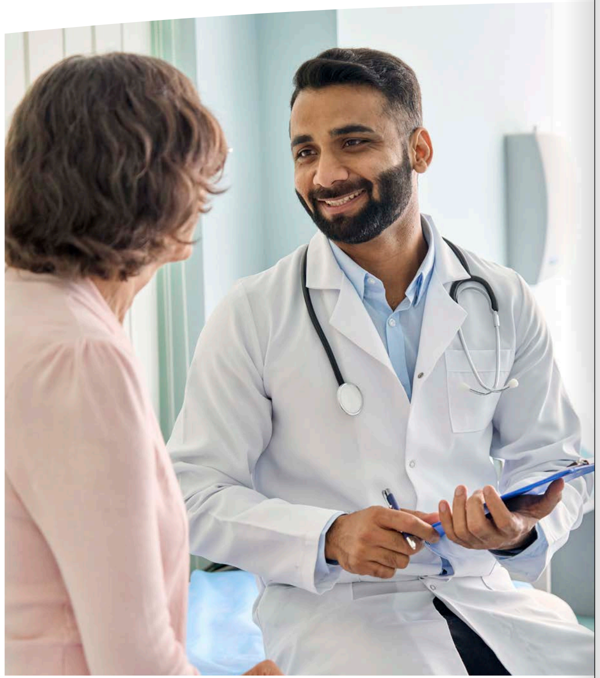
Less invasive procedures performed by an experienced neuroradiologist through a small opening in the groin or wrist:

Coiling

Tiny platinum wire coils are placed inside the aneurysm using a thin, flexible tube (called a catheter) that's guided through your blood vessels. The coils fill the aneurysm and help your blood form a clot, sealing it off while keeping normal blood flow through the rest of the artery.

Intrasaccular Devices

Special devices (Web™, Artisse™, Contour™) act like plugs in the aneurysm and work to block the blood flow and help your blood clot naturally. These work better than coils for certain aneurysm shapes and locations.



Stenting

A small metal mesh tube (called a stent) is placed like scaffolding across the aneurysm opening. This either holds coils in place or redirects blood flow away from the aneurysm, reducing the chance it will grow or bleed.

Flow diverters

Very fine mesh tubes used for large aneurysms. They work like a sieve, redirecting blood flow back into the normal artery while gradually causing the aneurysm to shrink and seal itself naturally.

Surgery

Performed by an experienced neurosurgeon:

Surgical Clipping

The surgeon accesses the aneurysm directly through a small surgical opening. Using a special microscope and tiny instruments, they place a small metal clip at the base of the aneurysm. This clip blocks blood from entering the aneurysm, preventing it from growing or bursting, to permanently stop blood from entering it. Surgical clipping is a durable treatment option.

→ Go to Step 7

Important note

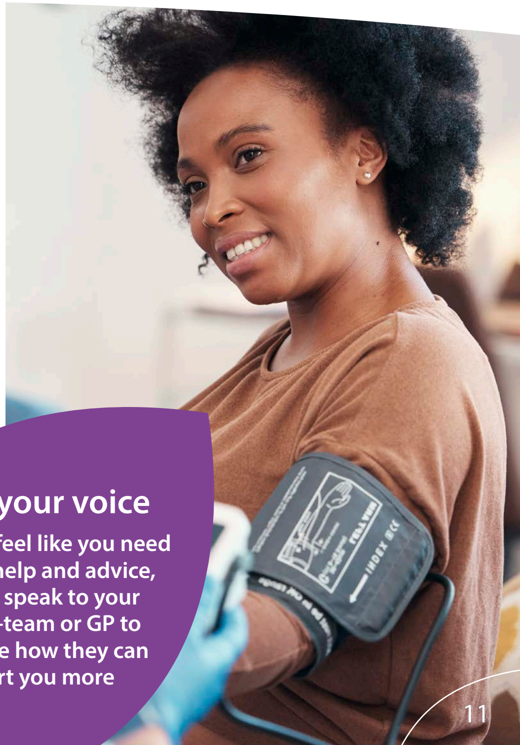
Every treatment holds a risk which your specialist team will talk you through. The treatment route chosen will be personalised to your aneurysm and medical needs. All methods are 'tried and tested' and hundreds of these procedures take place every week within the NHS.

STEP 7:
Ongoing care & support

Your journey doesn't end here. Whether you're being monitored or treated, you'll likely have:

- Regular check-ups and scans
- Access to a neurovascular nurse for support and questions
- Information for your family about their risk and screening options
- Support from specialist charities such as HBA Support

You're not alone – and you're not expected to manage this all at once



Use your voice

If you feel like you need more help and advice, please speak to your Neuro-team or GP to explore how they can support you more

Living well with a brain aneurysm

The good news is that most brain aneurysms stay small and never cause harm. With the right care and lifestyle choices, many people live full, healthy lives

Top tip

When buying any over-the-counter medicine, tell the pharmacist you have a brain aneurysm – they can advise on what to take and what to avoid

Why lifestyle matters

Research shows that certain lifestyle choices can help reduce the chance of an aneurysm growing or rupturing:

- **Manage blood pressure** – high blood pressure puts extra strain on aneurysm walls. Your GP can help you get yours to a healthy level and keep it there.
- **Try to quit smoking** – smoking weakens blood vessels and raises your risk. For help quitting, speak to your GP.
- **Drink moderately** – binge drinking causes blood pressure spikes.
- **Avoid recreational drugs and energy drinks** – these could increase your risk.
- **Check new medications and supplements** – speak with your doctor before changing these to make sure they don't increase your risk.

Some common medications can increase bleeding risk or affect blood pressure. Always check with your GP or pharmacist before taking:

Aspirin and ibuprofen (anti-inflammatory painkillers) are not advised: Always talk to a medical professional before taking these

Decongestants (found in cold/flu remedies) can raise blood pressure

Herbal supplements like ginkgo biloba may affect bleeding

Top tip

GPs and pharmacies offer free blood pressure testing

Common myths

Ignore common misinformation online – having a brain aneurysm doesn't mean life has to stop! We've made a list of the most common concerns.

You can get insurance

Insurance will be available to you. Speak to your insurance company about any treatment or diagnosis you may have. They can help and advise you. And do shop around for a good price.

You can usually drive

In many cases, you can continue to drive a car. You're advised to check with DVLA and your specialist for advice on your circumstance.*

You can get a mortgage

An unruptured aneurysm rarely affects mortgage applications.

You can exercise

Walking, swimming, yoga, and cycling are great for your heart, brain and vascular health. If you like to do intense or high-risk activities like contact sports, HIIT and weightlifting, please check in with your neuro specialist or GP for advice.

You can travel

Flying is usually safe but if you have any questions, do speak to your specialists. Bringing medical documents along with you on your journey may be a good idea. Do tell your travel insurance company about your diagnosis or screening.

You can keep working

Most people continue in their job with no restrictions but speak to your employer if you do need any help.

Remember: Everyone's situation is different: talk to your medical team about what's safe for you

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*See www.gov.uk/contact-the-dvla

Who's who: people you may interact with on your journey

Interventional neuroradiologist

A specialist who performs minimally invasive procedures to treat brain aneurysms, such as coiling or stent procedures. They often work alongside a neurosurgeon. You may meet them if this type of treatment is being considered.

Neuroradiologist

An expert in brain scans like MRI, CT, or angiograms. You'll usually never meet them directly, but they interpret the images that help diagnose and monitor aneurysms.

Neurosurgeon

A specialist in brain surgery. You may meet them early on for advice, especially if surgery is being considered.

Neurovascular nurse specialist

You'll usually meet them at diagnosis. They're available to answer questions and help you navigate your care.

Psychologist or counsellor

Supports your emotional wellbeing. Ask to be referred if you're feeling anxious, low, or having a hard time adjusting. They can help at any stage.

> "As specialist clinicians, we support patients in making informed decisions about screening. Knowing your family history is essential."
>
> Catherine Lamb,
> Neurovascular Advanced
> Clinical Practitioner

Genetic counsellor

Helps you understand how aneurysms can run in families and what this means for you and your relatives.

They can:

Explain the pros and cons of screening tests.

Talk about your family's risks.

Support you in talking to your family members.

Be prepared to ask for this service

Not all healthcare professionals automatically think to offer genetic counselling for brain aneurysms, but it's available if you ask for it. Genetic services have long waiting lists, so ask early on. When speaking to your healthcare team, you can say:

"I'm concerned about the hereditary aspects of brain aneurysms in my family – could genetic counselling help?"

Takeaway

Whatever stage you're at, there will be someone to support you. Reach out to HBA Support if in doubt or if you're unsure where to go.

Your family history

Understanding your family history is crucial for hereditary brain aneurysms. Use this space to map out any history of brain aneurysms, strokes, or sudden deaths that might be related.

First-degree relatives

Your closest blood relatives: Parent, brothers, sister, sons, daughters.

Name	Relationship	Age at diagnosis
Name	Relationship	Age at diagnosis

Second-degree relatives

Grandparents (maternal and paternal), aunts and uncles (your parents' siblings), grandchildren, nephews and nieces.

Name	Relationship	Age at diagnosis
Name	Relationship	Age at diagnosis

Other relatives

Half-siblings, cousins (particularly first cousins), any other blood relatives with brain aneurysms or unexplained sudden deaths could be relevant.

Name	Relationship	Age at diagnosis
Name	Relationship	Age at diagnosis

Additional notes

Note down your family history for type of brain aneurysm (if known), whether it ruptured (burst) or was found during screening, any treatments they received.

Bring this information, along with any relevant medical documents e.g. family member health reports or diagnostics, to your GP appointment or specialist consultation.

Talking with family

If an aneurysm is found or if you are researching family history, you may want to speak with close relatives. These conversations can sometimes be difficult.

When and how to start the conversation

Go at your own pace
Give yourself time to process first.

Choose the right moment
Quiet, one-on-one chats are often easier.

Be prepared
Bring helpful resources, like HBA Support's How to Talk to My Family guide, download at hbasupport.org.

Ask for support
Your nurse or genetic counsellor can guide you.

If you need help

Ask your GP or specialist for a referral to a **genetic counsellor**.

They can also help you **talk to family members** if that feels hard.

Remember: **every family is different** and you know yours best.

Helpful ways to explain things

"It's a small weak spot in a blood vessel, a bit like a balloon"

"This can run in families, which is why I wanted you to know"

"Having a family link doesn't mean you have one, just a slightly higher chance which you may like to explore"

"There may be a screening option if you ever want to look into it"

"It can be monitored and managed"

For more support and a full guide to family conversations (including how to talk with children), visit

hbasupport.org

> **"Having a conversation about an inherited condition in a family can feel difficult and overwhelming. Handled sensitively and at a speed that is right for family members, most people appreciate being given the opportunity to talk about their family history, so that they have options, even if they choose different paths to you."**
>
> Prof. Julian Barwell, Genetic Consultant

My notes and questions

> **"Read about your diagnosis, ask questions and keep asking until you are satisfied it has been answered, share your worries and fears as this can help to alleviate them a little"**
>
> Survey respondent

Questions for my GP/healthcare specialists

My concerns or worries

Things I want to remember

Important dates, appointments and actions to take

Other notes

Remember: No question is too small or unimportant. Your healthcare team is there to help you understand your condition and make informed decisions about your care.

Resources

Support organisations

HBA Support
www.hbasupport.org
support@hbasupport.org
UK's first patient-led charity for brain aneurysms. Offers information, an online community, and practical support.

Brain and Spine Foundation
Free Helpline: 0808 808 1000
www.brainandspine.org.uk
Offering peer support, creative groups, and resources. Specialist nurses offer support for those affected by neurological conditions.

The Brain Charity
0151 298 2999
www.thebraincharity.org.uk
Practical help and emotional support for anyone affected by a neurological condition.

Gene People
Genetic Helpline: 0800 987 8985
www.genepeople.org.uk
Support and advice for people living with genetic conditions.

Rare Minds
www.rareminds.org
Mental health services tailored to people with rare conditions.

ROAR Study
www.roarstudy.co.uk
For more information on the world's largest study focused on the management of patients with unruptured intracranial (brain) aneurysms.

Further reading

(via HBA Support:
www.hbasupport.org)

- The Science & Genetics Behind Familial Aneurysm Syndrome
- The Role of Genetic Counsellors
- How to Talk to My Family About My Condition
- Living with Health Anxiety
- Understanding Familial Brain Aneurysms

Important - Please note:

This guide provides general information and should not replace professional medical advice. Always speak with your healthcare team about your individual situation.

> "What struck me most about HBA was how personal the support felt. I had so many questions and didn't know where to turn. It's not just a website – it's people who really care"
>
> Lorna

For the latest updates, resources, and support, visit

www.hbasupport.org

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