

# Living with health anxiety

**Our guide has been reviewed by genetics professionals working in the NHS today. This is a guide for your information and consideration and does not constitute medical advice. We always recommend you discuss any concerns or medical worries with your GP and/or relevant consultant.**

*Brain aneurysms run through my family. I'm considering screening but worried about the results, what should I do?*

Deciding whether to undergo screening can be challenging, but it's important to remember that you're not alone in this process. Start by discussing your family history and concerns with your GP. They can help guide you towards the right specialists who will explain your options and potential pathways.



## **I'm confused about screening**

The decision to undergo screening is entirely personal. There is no right or wrong answer, and there's no need to rush. Take your time and choose what feels right for you and your unique circumstances.

## **I'm scared of what I might find out**

Although the risk may be small, and even though most aneurysms are treatable, it's worth considering how you might feel if you were found to have an aneurysm.

While brain aneurysms are more common in families with a history, it's important to remember that not everyone in such a family will develop one.

Consider how you feel about different treatment paths, including the "watch and wait" approach (see question 2 for more information on this), and remember it's your decision as to whether you opt for screening. There is no right answer or one-size-fits all.

While it's natural to fear the results, screening can provide peace of mind. There are various ways to monitor an aneurysm and reduce its risks.

Also remember that aneurysms are treatable through tried and tested methods. With specialist care, they can be transformed from a serious risk to something fully curable.

## **Screening facts**

Screening may be an option if you're eligible.

At present, there is no genetic test to determine if you have the hereditary condition linked to brain aneurysms. However, researchers are working to identify the genetic cause, which may one day lead to a blood test for diagnosis.

For now, screening is done through brain scans. The two main types are:

- **Computerised Tomography Angiogram (CTA)**
- **Magnetic Resonance Angiogram (MRA)**

Both scans are painless and don't require an overnight stay. Your consultant or specialist will recommend the most suitable option for you.

Results are typically available a few weeks after the scan, once analysed by a specialist.

## How you can support yourself

- **Speak to your GP, or your neurosurgeon or neuro vascular specialists** if you have already been referred, they can support you.
- **Speak to a genetic counsellor:** Ask your GP for a referral to a genetic counsellor but do keep in mind there is a long NHS waiting list for appointments with these specialists who can help you better understand your condition and how it may affect your family. Genetic counsellors provide a supportive, non-judgemental space to discuss your options, including whether anyone else in your family might benefit from screening.
- **Engage with support systems:** Don't go through this alone. Involve family or friends or consider talking to a professional counsellor or support worker who can offer emotional support.
- **Focus on what you can control:** Prioritise a healthy lifestyle with regular exercise, a balanced diet, and avoiding smoking or excessive alcohol. It's also important to maintain a healthy blood pressure.

*I have been diagnosed with brain aneurysms and have been told that they will "watch and wait" how it develops. I am now full of worry and anxiety. How can I live it's the worry of this every day?*



A 'watch and wait' treatment plan is when your specialist has recommended a monitoring pathway rather than treat surgically straight away. There are many reasons for this and factors that make up that recommendation. Your surgeon will weigh up the risks and benefits for surgery based on the shape, size and location of aneurysm as well as your ability to live with it psychologically, and your family history. It's completely normal to feel anxious when facing the uncertainty of a brain aneurysm. To ease your concerns, speak with your specialist or neurosurgeon—they can help you understand the facts and the reasons why they have recommended to 'watch and wait'.

Most unruptured aneurysms are symptomless and have a low risk of rupture (less than 0.5% per year). Thousands of people live with unruptured aneurysms without complications, which may help ease your fears. You'll also receive regular "watch and wait" scans to monitor any changes in size or shape. This proactive approach ensures that any changes are detected early, offering you peace of mind.

## How you can support yourself

- **Ensure regular monitoring:** Create a regular screening schedule with your specialist. The knowledge that you're under constant observation can assist ease your anxiety about the future. Talk to your neurosurgeon or neuro vascular specialist to make a joint decision based on what is right for you and your circumstances.
- **Seek professional support:** Speaking with a mental health professional who specialises in health issues can help. You can either ask your GP for a referral to a therapist or, if you can and have resources, see a specialist privately. Therapists and

**If the anxiety feels too much, professional support or even talking to someone who's been through this before can be incredibly helpful. Always reach out for help.**

trained specialists can provide tailored strategies to manage anxiety and stress. There are also a number of **free resources** available that offer immediate and accessible care. See signposts below.

- **Join support groups:** Connecting with others who share similar experiences can be reassuring. Both in-person and online groups offer a space to share and learn from others who understand.
- **Explore mindfulness techniques:** Practices like meditation, yoga, or deep breathing can reduce anxiety and promote relaxation.
- **Stay informed but set limits:** While it's good to be informed, too much research can increase anxiety. Set boundaries on how much time you spend reading about brain aneurysms. Also do keep in mind that not everything you find will be reliable or true. As you may be vulnerable to misinformation, please try and take care and find responsible information.
- **Focus on what you can control:** Prioritise a healthy lifestyle with regular exercise, a balanced diet, and avoiding smoking or excessive alcohol. It's also important to maintain a healthy blood pressure.
- **Communicate openly:** If you're able and comfortable, share your feelings and worries with loved ones. Honest conversations can offer emotional support and help others understand what you're going through.
- **Consider an alert bracelet:** These can be worn inside and outside the home and they are freely available. Health apps, as well as the medical alert bracelets, can inform or alert health professionals if you were to fall ill.



*I have just been diagnosed with a brain aneurysm and have been told they'll treat me surgically soon. I am now worried about the procedure and treatment. What can I do to manage my anxiety?*

**Write a list and ask your doctors any questions on your mind. Being informed can help lessen the anxiety of uncertainty. If you're unsure, always ask for more support.**

It's natural to feel anxious during this time. It's also natural to have a need for responsible and balanced information. Some people like to find everything they can about their condition and the details of the procedure, others prefer just the informed, easy to understand headlines. Have a think about what level of information you would like and share this with your specialist team. They can then explain the details, and what to expect after surgery, helping to reduce any confusion or worry in a way that works for you.

Do keep in mind that modern brain aneurysm surgeries have advanced significantly, with many procedures now being minimally invasive and offering quicker recovery times. Trust in your surgical team—they have likely performed these procedures many times before, and their expertise will guide you through the process.

If you have decided to go through treatment, or are still considering the next steps, remember, the goal of the surgery is to prevent more serious outcomes and your neuro team will be able to talk you through the risks, the benefits and the recovery afterwards. They are there to support you every step of the way.

## How you can support yourself

- **Consider mindfulness and relaxation:** Practices like yoga, meditation, and deep breathing can help calm your mind. There are various online tools and apps available to assist with these techniques.
- **Engage with support groups:** Connecting with others who have similar diagnoses can provide both practical advice and emotional support. Many hospitals offer support groups for patients with brain aneurysms.
- **Seek professional assistance:** Consulting a therapist or counsellor specialising in medical anxiety can be beneficial. Cognitive-behavioural therapy (CBT) is one option to consider.
- **Stay active: If your medical team allows, stay active through gentle exercise.** It can help to boost your mood and reduce anxiety. Always consult your doctor before making any changes to your activity level.
- **The Royal College of Anaesthetists** have a useful guide and resources here on how to prepare for surgery: [Preparing your mind before surgery | The Royal College of Anaesthetists \(rcoa.ac.uk\)](https://www.rcoa.ac.uk)

## General Top Tips

**You are unique. What's important is that you do what's right for you and your health. Always speak to a trained medical professional for advice and guidance.**

**Take healthy lifestyle decisions:** Make lifestyle choices including controlling your blood pressure and abstaining from smoking lowers your chance of developing an aneurysm. Your general vascular health can be enhanced by eating a balanced diet and exercising regularly.

**Prioritise stress management:** Practicing stress-reduction methods like yoga, meditation, or even speaking with a therapist can help you healthily manage anxiety.

**Try Cognitive Behavioural Therapy (CBT):** CBT strategies can assist you in recognising and addressing anxious thoughts. It assists you in reframing irrational or pessimistic thoughts into something more sensible and balanced.

**Consider therapy:** Having a conversation with a therapist can assist you in managing the emotional burden of bearing this risk. They can teach you techniques to address ongoing worry without letting it dominate your thoughts. Speak to your GP about how to access one.

**There are also lots of other techniques available for you to try:** Different techniques work for different people, so it's important to find what works for you. Some people find journaling - that writing down your thoughts and feelings can help you process your emotions - helps. Others Practice Gratitude and Mindfulness and try to appreciate each moment as it comes is possible when you find a balance between alertness and acceptance. And remember, always speak to a trained medical professional for advice and guidance on how to manage your physical and mental health.

## More information and support

HBA Support is here to support you and your family through your journey. We have lots more information available to individuals and their families such as guides on:

- **The Science & Genetics Behind Familial Aneurysm Syndrome**
- **An Introduction to Genetic Counsellors**

Please take a look at our support pages to find out more: <https://www.hbasupport.org/support>

## Other Support

There are also lots of other charities and support groups available to you. Here are a few for you to consider:

- Tailored and useful information can be found on the **Rare Minds** website. <https://www.rareminds.org/wellbeing-hub/diagnosis/early-days/>
- Speak to a trained specialist Neuro Nurse through the **Brain and Spine Foundation's** free helpline: 0808 808 1000 <https://www.brainandspine.org.uk/>
- **NHS Lothian** have a useful guide for patients: <https://services.nhslothian.scot/geneticservice/wp-content/uploads/sites/54/2022/07/Information-for-adults-considering-screening-for-brain-aneurysm.pdf>
- **Brain Aneurysm Foundation (A US Charity)**: <https://www.bafound.org/understanding-brain-aneurysms/warning-signs-symptoms/diagnosis-and-screening/>
- Develop your own personalised mental health action plan here through the **NHS's Mind Map** resource: <https://www.nhs.uk/every-mind-matters/mental-wellbeing-tips/your-mind-plan-quiz/>
- **British Heart Foundation** has some useful information on how to live with health worries: <https://www.bhf.org.uk/information-support/heart-matters-magazine/wellbeing/stop-worrying-about-health#Heading3>
- **NHS** support and guidance can be found here: <https://www.nhs.uk/mental-health/conditions/health-anxiety/>
- **Very Well Mind** has useful information on how to manage anxiety and worry: <https://www.verywellmind.com/3-3-3-rule-for-anxiety-8660964>
- **Gene People** provide support and information. They also offer a genetic counsellor helpline for those who are looking for, or dealing with, a diagnosis, 0800 987 8987 <https://genepeople.org.uk/>
- **The Royal College of Anaesthetists** have a useful guide and resources here for people about to go through surgery: <https://www.rcoa.ac.uk/patients/patient-information-resources/preparing-your-mind-surgery>
- A useful guide on coiling from the **Brain and Spine Foundation** can be found here: <https://www.brainandspine.org.uk/health-information/fact-sheets/coiling-of-brain-aneurysms/>
- **Mind**: Please visit MIND for free mental health support <https://www.mind.org.uk/>

Hereditary Brain Aneurysm Support would like to sincerely thank Chandana Veshala for her hard work and expertise in preparing this guide for our community on a voluntary basis.

With many thanks to

