

How to talk to my family about my condition and potential options for screening

This guide is for you if you have been diagnosed with a brain aneurysm which is highly likely to be hereditary (sometimes called familial). It will help you share your diagnosis with your family members, talk to them about their screening options and their possible hereditary risk. Our guide has been prepared by a genetics professional 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.

Talking to adult family members

How to share news about your diagnosis or worry that the condition may run in the family.

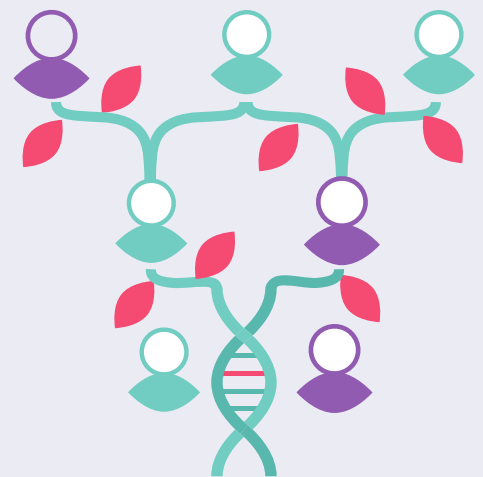
Information can be shared when you feel it is the right time. It may take some time for you to understand your new diagnosis and the possible emotions attached to it such as anxiety and sadness. Take your time to find the right moment for you.

How to share this with your family may depend on how close you are, the age of family members and their geographical location. How you contact family members is your choice. It may be worth considering having one-to-one conversations with them rather than at a family celebration or gathering as they will also need time to process the information and ask questions. Find a time and space for you all to talk and ask questions. Having information to hand or on your phone may also help you explain. Take a look at our genetics guide on [our website](#) for more useful information on how to explain the hereditary patterns.

If you don't see or speak to your extended family often it might be worth thinking of ways to talk to them. This could be over telephone, social media or by letter. It may be helpful to think about how you would like to be told if you were in their shoes. Again, feel free to link to more information, for example the HBA Support website or the NHS website.

What can I do to prepare?

It can be useful to think about how much information each family member may want. You may be asked a lot of questions and so make sure you have this information available or be



able to signpost to websites or leaflets so they can read more about the condition. There is information and links on HBA Support's website, www.hbasupport.org.

It may be worth jotting these down so you can easily pass them on to family members or saving useful links on your phone.

What words should I use?

How consultants and nurses describe your condition can sometimes change. Take a look at our genetic guide at www.hbasupport.org to help you explain the hereditary patterns and risks. Trust your instincts to find the right words and descriptions with your family, you know them best.



Which family members will get referred for screening? What should I advise?

Family members who have multiple first and second-degree family members with brain aneurysms could be referred into specialist neurologist or genetic services via their GP for discussions around screening. If relatives have headaches or neurological problems, they should also receive support early if there is a family history.

First degree relatives are your mum, dad, sister, brother, or child. Second-degree relatives are your grandparents, aunt, uncle, or cousin.

Current NHS approved recommendation says that if you have you had/have two or more first-degree relatives (father, mother, sister or brother) who experienced a subarachnoid haemorrhage, which is a burst aneurysm, or they have a confirmed diagnosis of a brain aneurysm then you should consider screening. This done through a brain scan.

That said, if you have a strong family history but you don't fit exactly within this approved recommendation please still do talk to your GP. For example, patterns of aneurysms are also important as is what age people were diagnosed or first treated. If there are multiple first and second-degree family members with ruptured or unruptured brain aneurysms and other aneurysms such as aortic aneurysms screening may also be possible.

Speak to you GP who will be able to refer you to a specialist for further assessment. They may also refer you to a genetic counsellor for advice and support, who will take a closer look at your family history. Take a look at our guide about what a genetic counsellor does for more information at www.hbasupport.org.

I'm not sure I can share the information with my family, what can I do?

Sharing a diagnosis of hereditary brain aneurysm can bring up many emotions within your family especially when 'hereditary' is in the name. More so if you and your family have suffered loss or great upset due to a subarachnoid haemorrhage or a brain bleed in your family. You may have even lost close family members. If you feel additional support is needed, then please ask for help. Your GP or neurologist can refer you to a genetic counsellor. They could assist you in contacting other

close family members who may want to consider screening. Please do contact them for further advice and help.

If you feel comfortable, it may be helpful sharing your letters from your consultants or specialists or bringing family members to your appointments so they can find out more. Pointing them towards the HBA Support website could also help.

Lastly, it's important to highlight that every family is unique and may respond in different ways. You know your family best and ultimately how and when to discuss your diagnosis and screening with them.

Remember, your diagnosis is down to your genetic make-up, it's nothing you have done. It is a condition you have likely inherited through no fault of your own.

Talking to young people

Risk in Adulthood

According to NHS guidelines, if eligible, screening for a brain aneurysm can start from 20 years of age. This is because specialists believe the risk of developing an aneurysm starts in adulthood. Luckily aneurysms in children are extremely rare. So, whilst children or young adults would not access screening, except in very exceptional circumstances, it may be helpful telling them about your condition in a gentle way to prepare for possible future screening. They can be very observant so could notice a parent or family member going to hospital appointments.

Drip feed approach

A drip feed approach is believed to be one of the best ways of sharing information to children and young people about hereditary conditions. Fewer negative impacts have been seen when small bits of information are shared over time through childhood rather than all the information in one day.

Relatable information

It can be helpful using relatable information such as from TV programs or school homework to help children to understand. Check their understanding throughout discussion and correct any confusions. It can also be useful to think about the language. The word 'aneurysm' is a difficult word, perhaps you could use a 'bubble' from an artery, or a 'balloon'. 'Hereditary' and 'familial' are also complicated terms. 'Passed down' or 'through the family' could be a better alternative. The age of the child will guide the language and level of detail you may choose to use.

How best to support your children

Encourage children to ask questions, and where possible try to answer. You don't have to have all the answers you can learn together with your child. There is no perfect age but consider the child's individual maturity level and development stage.

Screening options

If you are eligible for screening, please remember deciding to have or not have screening is a personal choice and one that there is no rush to make. It's important to do what you feel is right for your physical and mental health. There is no right or wrong answer, you must do what is right for you and your circumstances.

There is no blood test available to see if you have the hereditary condition. Hopefully, once researchers have found the genetic cause, there may be a time when a blood test can diagnose your risk. Until that time, screening is done through brain scans.

Types of Screening: There are two main types of screening: Computerised Tomography Angiogram (CTA) or Magnetic Resonance Angiogram (MRA) scan. These scans are painless and will not require an overnight stay. Your consultant or specialist will be able to advise you which is recommended for you. You should receive your results a few weeks or so after your scan, once it has been analysed by a specialist.

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.

Positive steps you can take to look after yourself

There are some lifestyle factors which will help keep all your vascular system (your arteries and veins) in good working order. Things that are good for your heart are also good for your brain's vascular system too.

If you or a family member is diagnosed with a brain aneurysm, lifestyle changes such as stopping smoking, reducing alcohol content, gentle exercise and lowering blood pressure can help reduce risk and keep you healthy.

Please speak to your GP or consultant if you need any further advice and help on how to look after yourself.

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

Information sources:

1. <https://www.hbasupport.org/uploads/brain-aneurysms-research/brain-aneurysm-research.pdf>
2. https://policyonline.nhslothian.scot/Policies/PatientInformation/Information_for_adults_considering_screening_for_brain_aneurysm.pdf
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8. <https://www.xrayrisk.com/calculator/calculator-normal-studies.php>
9. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1084214/UKHSA-CT-report.pdf

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