

The role of genetic counsellors

This guide was 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.

What is genetic counselling?

Genetic counselling involves talking to a specialist to help you understand more about your condition and how it runs in your family. Genetic counsellors can provide a non-judgemental safe space for you and your family to discuss the different options available to you and can help you access further support.

A genetic counsellor can help you understand:

- The risks and benefits of having a specific genetic test (if applicable)
- The risks and benefits of any available screening
- How other family members may be affected
- The risks of passing on a health condition to your children

Currently, there is no specific genetic test for familial brain aneurysm syndrome. However, there are tests for some situations where there may be a link to other conditions. If there is felt to be a history of renal cysts or a connective tissue disorder called Marfan's syndrome you can be tested for these as they are associated with increased risk of aneurysms.

How can I access the service?

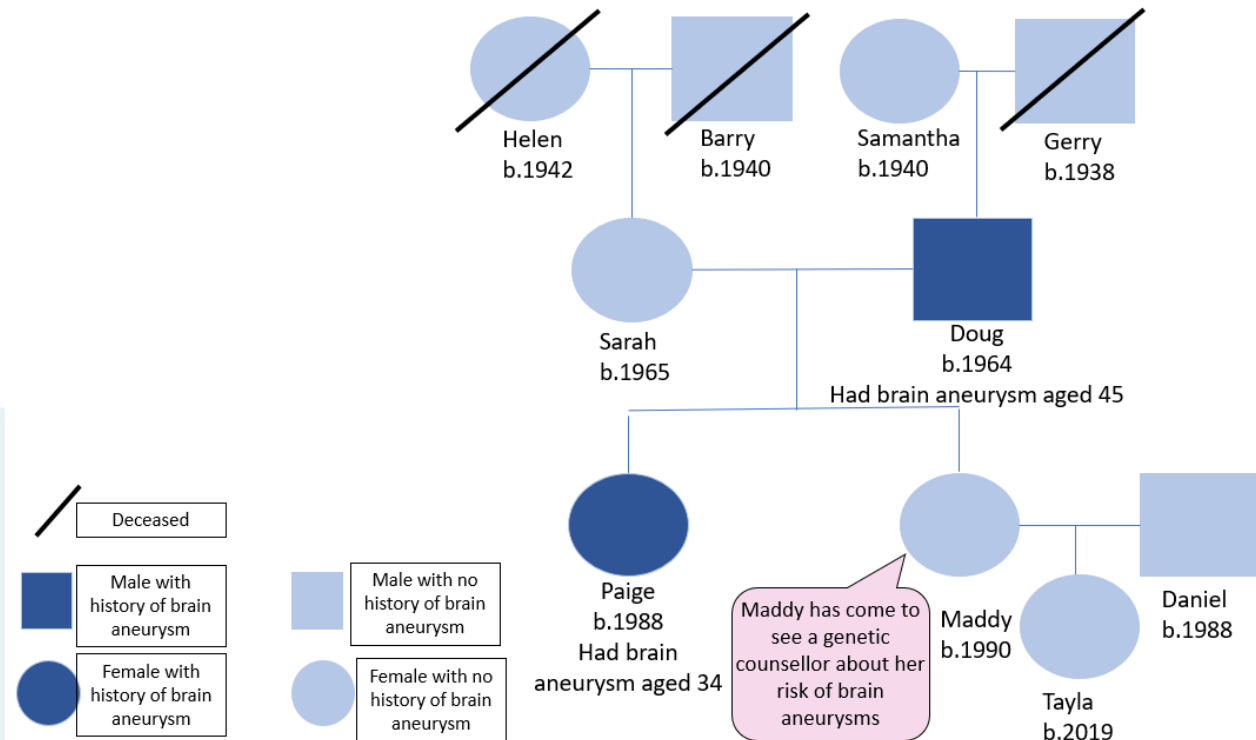
Talk to your neurologist or GP to see if talking to a genetic counsellor could be beneficial to you or your family. They will refer you to your local genetics service.

What happens in a genetic counselling appointment?

Appointments typically last between 30 and 60 minutes. They can take place over the phone, over video or face to face in the hospital.



The genetic counsellor may take a family history. They may draw a diagram called a family tree. This will show your close blood relatives, how they are related and their illnesses. The genetic counsellor may also ask for your medical information to further understand your risk of having the condition.

Example of a family tree diagram with information about family members


The genetic counsellor may discuss the condition and how it has been passed down in your family. They may show you some diagrams to help you understand the condition. They may discuss your risk of having a condition and the risk of passing this down to your children.

They will be able to discuss management of the condition with you and discuss if you are eligible for screening and how to access it. If needed, they can refer you to a specialist, such as a neurologist.

What information will I be asked for?

The genetic counsellor will ask you about your family members including your parents, grandparents, siblings and any children you have.

It will be helpful if you know rough ages of the members of your family, any medical diagnoses they have and a rough idea of when they were diagnosed. Do not worry if you cannot recall exact information.

It can be difficult to discuss family history for some people, but it's useful for the genetics department to have this information so that they can give you an accurate estimation of your risk.

How can I make the most of the appointment?

There may be questions you would like to ask the genetic counsellor. You may like to write these down before your appointment. Some examples of questions you might want to ask are:

- What is my risk of familial brain aneurysm syndrome?
- How sure are you of this risk?
- Who else in my family may be at risk?
- Do I need to inform my family members?
- Should I get screened?
- What lifestyle factors can I introduce to reduce my risk?
- What should I do if more family members are diagnosed with an aneurysms?
- How do I stay up to date with current research or healthcare recommendations?



You may find it helpful to bring a partner, a family member or a friend to the appointment with you.

The genetic counsellor is there to answer all the questions you have so do not be afraid to ask too many questions. After the appointment, you will usually receive a letter with all the important information from the session.

Feel free to give the genetic counsellor any information that you feel is important.

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

Where to get further information?

NHS: <https://www.nhs.uk/conditions/genetic-and-genomic-testing/>

HBA Support: <https://www.hbasupport.org/>

Gene People (genepeople.org.uk) have a free, genetic counselling helpline: 0800 987 8985.

Brain & Spine Foundation (brainandspine.org.uk) free, neuro nurse specialist helpline: 0808 808 1000.

Brain Aneurysm Foundation (please note that this is a US site): bafound.org

Information for adults considering screening for brain aneurysm by NHS Lothian:

<https://services.nhslothian.scot/geneticservice/wp-content/uploads/sites/54/2022/07/Information-for-adults-considering-screening-for-brain-aneurysm.pdf>

This guide has been made possible by a grant from Localgiving and Postcode Places Trust, a grant-giving charity funded by players of People's Postcode Lottery.

