

LIVING WELL WITH HAE

The Role of Genetic Counselling

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Watch the video: <https://haeaustralasia.org.au/resources/video-resources/>

WHAT IS GENETIC COUNSELLING? (VIDEO REF: 0:18)

Genetic counselling is essentially a communication process. It can be done by any health professional, but is probably best done by a genetic counsellor who is an allied health specialist who

- Is trained in genetic counselling
- has the time and the expertise to explain the genetic result to you
- can provide you with support and education

Often genetic results can mean that you have a genetic condition, which is lifelong and can be a confronting process. A genetic counsellor can be available to provide you with the time and an extra layer of support to help you adapt to that result.

WHAT'S INVOLVED IN GETTING GENETIC COUNSELLING? (VIDEO REF: 0:57)

A genetic counselling appointment is a discussion either face to face or virtual. The counsellor would collect your family history information, and usually it's about

- yourself
- your parents and your grandparents
- your children

Your family history is collected to help the counsellor inform their conversation with you and what that means in terms of the result and how that works. They can help you interpret the medical information, or assess whether you do have a genetic condition. Some tests may need to be done which is usually completed in conjunction with other doctors, either a clinical geneticist or sub specialist, like an immunologist in the case of HAE. The counsellor will talk you through the result and that might be done over several appointments, or via telephone and then in person.

WHAT IS THE ROLE OF GENETIC COUNSELLING FOR HAE PATIENTS AND THEIR FAMILIES? (VIDEO REF: 1:55)

For HAE, there are two important roles. First of all, making sure that the result is interpretable. The results for any genetic condition, can sometimes be difficult to interpret. Sometimes the results are really clear cut, it's been described in lots of other people before and the answer is known. In other people, there may be genetic changes but it's not clear whether there is actually an answer or not. A genetic counsellor can help you clarify the result by testing other people in the family and making sure that the uncertainty is explained and to help with how to communicate and deal with that through your family.

The other role of a genetic counsellor is explaining that this is an inherited condition, and is inherited in an autosomal dominant fashion which means every generation may be at risk. If you have the condition, there's a 50/50 chance of passing it on. If you were worried about the risk of passing the condition on to your children, there are potential options for you in terms of your own family planning. A genetic counsellor could discuss that with you or alternatively arrange testing for the rest of your family including children.

HOW DOES A PATIENT GET REFERRED TO SEE A GENETIC COUNSELLOR? (VIDEO REF: 3:21)

Genetic counsellors in Australia and New Zealand usually require a referral from either their GP or sub specialist like an immunologist. There are genetic services all over Australasia. You can be seen either in your Metropolitan Hospital or in a regional centre or with telehealth services, so if you can't make it in person, you can be seen from the comfort of your own home.