



# Genetic Counselling



## What is genetic counselling?

Genetic counselling is a confidential service which helps individuals and families understand the reasons why a neural tube defect has occurred during pregnancy and the risk of it recurring. When a neural tube defect is diagnosed, particularly during pregnancy, it has usually occurred as an isolated incident but on closer examination can be found to be part of issues which can have very different genetic implications for the future. Counselling can also provide support with any concerns and anxieties individuals may have. The aim is not to make decisions for people but to enable them to have the necessary understanding in order that they can make informed choices and decisions. It often makes things clearer when the issues involved are discussed with someone who has the expertise and understanding of them.

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## Who provides genetic counselling?

Genetic counselling is provided by someone with a health background who has had further training in genetics and counselling and usually takes place at a specialist centre.



## What happens at an appointment?

A family history is collected in order to provide information about the health of family members. This will enable the Geneticist to map out a family tree to find out if there is any relevant history of neural tube defects. Blood tests may also be carried out. The Geneticist will also help you to understand the results of any tests and interpret medical information about any risks present. A further appointment can be arranged if more information or tests are required and to answer any further questions you may have. A summary letter of the consultation is also provided. Often a Geneticist can determine the risk of occurrence or reoccurrence of a neural tube defect and if this risk is present you can speak with Spina Bifida Hydrocephalus Scotland's (SBH Scotland) support workers to discuss neural tube defects and their possible effects in more detail.



## How can I be referred?

You can ask to be referred by your GP. If you have had a pregnancy or a baby with a neural tube defect, a referral can also be made by the Obstetric or Paediatric staff. Some people find counselling helpful soon after the birth of a baby or termination of a pregnancy as they have urgent questions which they feel cannot wait. Others prefer to leave it a little while until they can think more clearly. A genetic consultation can also be useful if you or your partner have a neural tube defect such as spina bifida, to discuss the risk of a pregnancy being affected.



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If you have questions or would like further information, please call the **SBH Scotland Helpline** on **03455 211 300** or email **support@sbhscotland.org.uk**  
For general enquiries call **03455 211 811** or visit **www.sbhscotland.org.uk**

**This fact sheet is for informational purposes only. It is not intended to replace or be relied on as medical or professional advice. Contact us if you require this publication in another format or language.**

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