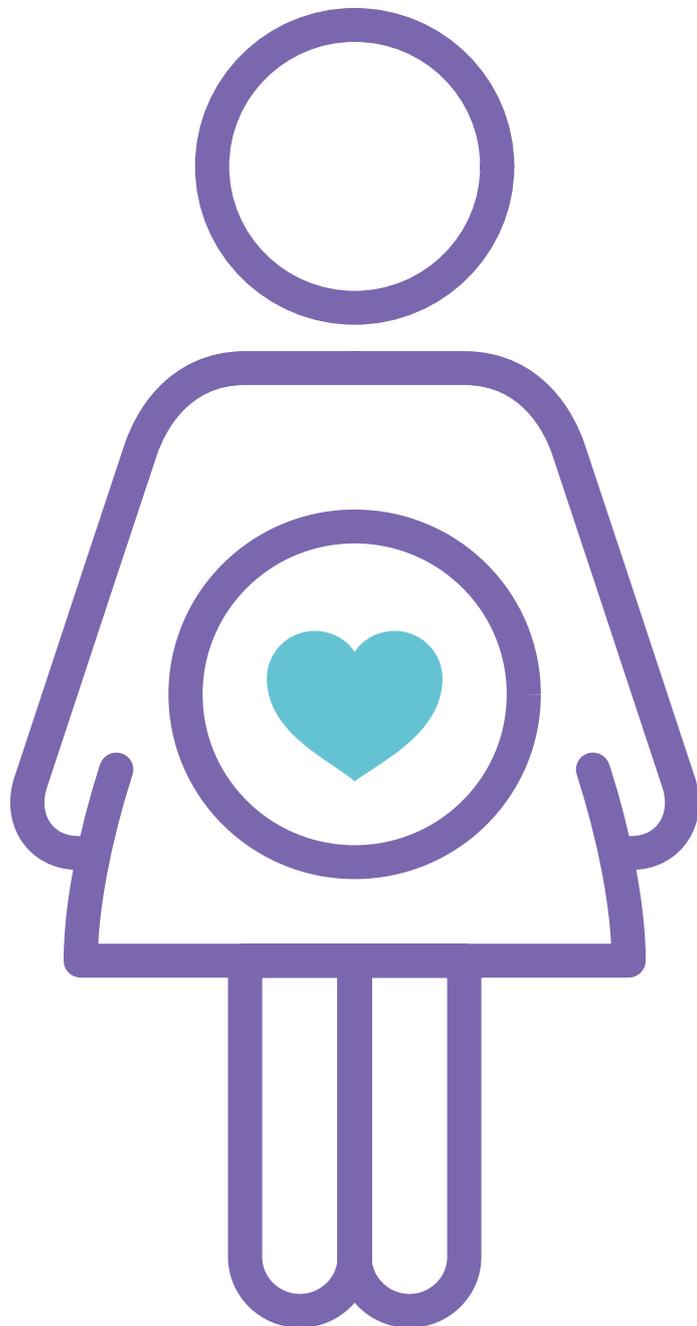


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Spina Bifida
Hydrocephalus
Scotland



Anencephaly





What is anencephaly?

The neural tube is a narrow sheath which folds and closes to form the brain and spinal cord between the 3rd and 4th week of pregnancy. Anencephaly is the failure of the head (cephalic) end of the tube to form properly resulting in the upper part of the brain and its protective skull cap being missing. There may also be missing bones around the front and sides of the head. It results in only minimal development of the part of the brain which controls high level functions such as thought processes and co-ordination, sight, hearing and consciousness.



How is it diagnosed?

The diagnosis is usually made during pregnancy. A routine blood test is offered to women between 15 and 20 weeks of pregnancy which detects the level of Alpha Feto Protein (AFP). Abnormal levels of AFP can indicate a number of things, one being a Neural Tube Defect. A detailed scan is then offered which will almost always indicate if anencephaly is present. Most Consultants in this case will recommend a termination, however some parents decide to continue until full term to provide the opportunity for them and their family to say goodbye. Occasionally, parents ask for the pregnancy to continue so that the baby's organs can be donated for transplant.



Can anencephaly be treated?

There is no medical or surgical treatment for anencephaly as the parts of the brain that are missing control all the higher functions that we need to live. Sadly, babies will often not survive for more than a few hours or days.

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What causes anencephaly and can it be prevented?

Firstly, it is important that you know that it has not been caused by anything you did or didn't do, and the causes of Neural Tube Defects are still unknown. However, if you have had a baby with anencephaly the risk of having another baby with a neural tube defect is 2.5 to 3% for siblings of an unaffected case and 3 to 4% for siblings of an affected individual.

The risk of it recurring can be reduced significantly by taking an increased daily dose of folic acid at least 12 weeks before becoming pregnant and continuing until the 12th week of pregnancy.

The increased 5mg dose of folic acid is only available on prescription from your GP and is recommended for the following groups of women:

- Those who have a NTD or a family history of NTD
- Those whose partner has a NTD or a family history of NTD
- Those with diabetes
- Those with coeliac disease
- Those taking anti-epilepsy medication



Is there a risk it will happen again?

Couples who have had a baby with anencephaly should have the opportunity of genetic counselling where you can discuss family history and the risk of a neural tube defect recurring in future pregnancies. It also provides the opportunity to discuss any particular concerns and anxieties and can enable couples to make informed decisions and choices. A referral can be made through the GP or the Direct Services Team at Spina Bifida Hydrocephalus Scotland (SBH Scotland).

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Is there anything else I should know?

Losing a baby, no matter what the reason, is always a devastating experience. At this time many people like to speak with someone they feel comfortable with. SBH Scotland's Support Workers are available to talk with you or we can put you in touch with a counsellor who can also help. Alternatively your own spiritual leader, if you have one, or the hospital Chaplain may be able to guide and support. Many hospitals also have specially trained Bereavement Counsellors available.

Some people find it comforting to have a funeral and Funeral Directors should be sensitive to your needs.

If there are other children in the family, it is often helpful for you to encourage them to write a letter or draw a card or picture for the baby that you can keep in a box of memories. Some hospitals have a Book of Remembrance to which you might like to contribute.



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.

Spina Bifida Hydrocephalus Scotland is a trading name of the Scottish Spina Bifida Association.
Registered Scottish Charity No. SC013328. Registered office: The Dan Young Building, 6 Craighalbert Way, Dullatur, Glasgow, G68 0LS.
A company limited by guarantee. Registered in Scotland Number 213050.

Updated August 2016 by SBH Scotland's Medical Advisory Group.

