Scottish SPINA BIFIDA Association

Anencephaly

One of a series of fact sheets produced by the Family Support Service

What is Anencephaly?
Anencephaly is an abnormal development of the brain and skull which occurs during the first weeks of pregnancy. The upper part of the brain and its protective skull cap are missing and the lower part of the brain and the base of the skull are not properly formed.

Sadly, this is always a fatal condition. Whatever anybody does, your baby cannot and will not live.

What causes Anencephaly?
Anencephaly is due to failure of the basic part of the brain to form during the first 24 days after conception.

More baby girls are affected than are boys and the incidence is higher in those geographical areas where spina bifida is more common. Some infants have spina bifida and anencephaly.

Is it caused by anything I did?
No, no one is to blame for your baby having anencephaly.

It occurs in about 1:1000 pregnancies.

The risk of having another affected baby is 1:50 and 1:5 if it has happened more than once. However, taking folic acid for at least one month before you become pregnant and continuing until you are 12 weeks pregnant can reduce the risk of recurrence by 72%. The dose you need is 5 mg a day, and you need to get this on prescription from your doctor.

Diagnosis
As you are now aware, this is by ultrasound scan and anencephaly may be detected as early as 12 weeks into the pregnancy.

What happens now?
A detailed scan will be done to confirm the diagnosis. After this, most Consultants will recommend that the pregnancy is terminated.

It is important that you understand that whenever your baby is born, the outlook is the same, he or she will not survive. For this reason, it may make the decision easier if you view the termination of this pregnancy as an early delivery.

Some parents elect to continue to term to give them and their other children time to say goodbye. Occasionally, parents ask for the pregnancy to be allowed to progress, so that the baby's organs may be donated for transplant.

Whatever you decide to do, this will be the hardest decision you will have to make and you need to discuss all your options fully with your Consultant.

Can anything be done to help you baby?
No, anencephaly is totally untreatable. The parts of the brain that are missing control all the higher functions that we need to live. These include sight, hearing, intellect, as well as personality and the ability to feel pain.

Most babies with anencephaly are stillborn or die in the first days after birth.

Will we be able to have a funeral?
Yes, and most Funeral Directors will be very helpful and sensitive to your needs; many will help arrange a funeral if the infant is born before 24 weeks gestation (when the foetus legally becomes a baby).

Your local Minister or Religious Leader will also be able to give you advice or you may prefer the hospital to make the arrangements.

How about future pregnancies?
Give yourself time to mourn for this baby and to recover from the trauma of his/her birth and death. Then, start taking 5 mg of folic acid at least a month before you want to be pregnant again.

If you are a smoker, try to give up now, as smoking can inhibit the efficiency of folic acid. If you are on anti-epileptic drugs, speak to your Neurologist about the effects folic acid may have on your medication. Once your pregnancy has been confirmed, ask your doctor to refer you for an early

scan; if negative you will be re-scanned regularly up to the 20th week of the pregnancy.

Is there anything else I should know?
Losing a baby for whatever reason, is always a devastating experience. You must expect birthdays, special family days and celebrations to be difficult for you for the first years.

Your other children will naturally want to talk about the baby and this too will be difficult. Perhaps it will help you all to encourage them to write a letter or draw a card or picture for the baby. This you could keep in a box of memories.

Some hospitals have a Book of Remembrance to which you might like contribute. The Family Support Workers are at the end of the telephone if you need to talk.

Some hospital Trusts have trained Bereavement Counsellors.

If you have any questions or would like further information, please do not hesitate to contact the Family Support Workers at:
Scottish Spina Bifida Association - Family Support Service
Address: The Dan Young Building, 6 Craighalbert Way, Cumbernauld, G68 0LS • Tel: 01236 794516 • Fax: 01236 736435
Lo-Call Helpline: 08459 11 11 12 • E-mail: familysupport@ssba.org.uk • Web: www.ssba.org.uk