

Pregnancy and Spina Bifida

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

It's natural for any woman to have some anxieties about pregnancy and childbirth but there are increasing numbers of women with spina bifida having children and the chances of having straightforward pregnancies and deliveries are very good. Before deciding to start a family you may want to know about the risk of your children having spina bifida. For women who have spina bifida, or whose partner has spina bifida, there is certainly a higher risk of having a child with the condition than there is in the general population. However, even with the increased risk, the chances are still much more likely that your children will not have spina bifida. We would recommend you be referred to a Genetic Counsellor by your GP for specialist advice.

Once you have decided to start a family, but before you get pregnant, make an appointment to see your GP. He should send you to see a Urologist to check your kidneys, and Neurosurgeon if you have a shunt. If you are taking any medication ask your doctor what its effects will be, if any, on the baby. It is important that you also seek advice about taking folic acid which can help prevent spina bifida and ideally this should be started 12 weeks *before* conception and until 12 weeks *after*. If you are considered at higher risk you will be advised to take the larger dose of 5 mgs which is only available on prescription.

Antenatal care

You can ask to have a large part of your antenatal care at home which could be more convenient if the surgery or clinic is not easily accessible. Have a chat with the Community Midwife to discuss the options.

Screening

Various checks are carried out during pregnancy to ensure the baby is developing as expected and to detect possible abnormalities and these should be discussed fully with your Consultant.

Antenatal classes

Ask if notes about your continence management and other important information about your disability can be kept with your notes at the antenatal clinic. This can avoid the need for repeating explanations to every health professional you meet during your care.

Do make the hospital aware of the extent of your condition right from the start of your pregnancy.

You should ask to look round the maternity ward and delivery suite to see if there are likely to be any access problems and ask if the hospital can find ways round them.

During pregnancy

As your pregnancy progresses you may feel breathless as the enlarging womb makes chest expansion more difficult. If so, you may need some physiotherapy to help with breathing.

Extra care will need to be taken to avoid pressure sores if you are a wheelchair user, because of the extra weight you will put on during pregnancy. Long periods of sitting in your chair may also increase the possibility of swelling of the feet and ankles. Do check your skin carefully and frequently for any signs of redness that could develop into pressure sores.

Birth and After

Most hospitals provide the opportunity for you to write a birth plan that is a general outline of how you want things to happen. The plan is a way of making sure that those caring for you know your wishes and can discuss them with you. You may also want to know if you can have an epidural as a method of pain relief.

Breastfeeding

It is generally recognised that breastfeeding is best for babies and if this is what you choose then you may need to adapt the positioning for feeding. A breastfeeding counsellor should be able to help you with this and can be contacted through your midwife or the National Childbirth Trust.

Going Home

All new parents can find it very hard to adjust to the physical and emotional demands of a new baby. You may want to ask for some help and your Health Visitor can advise about the help that is available. You can also contact the Family Support Service for advice.

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

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