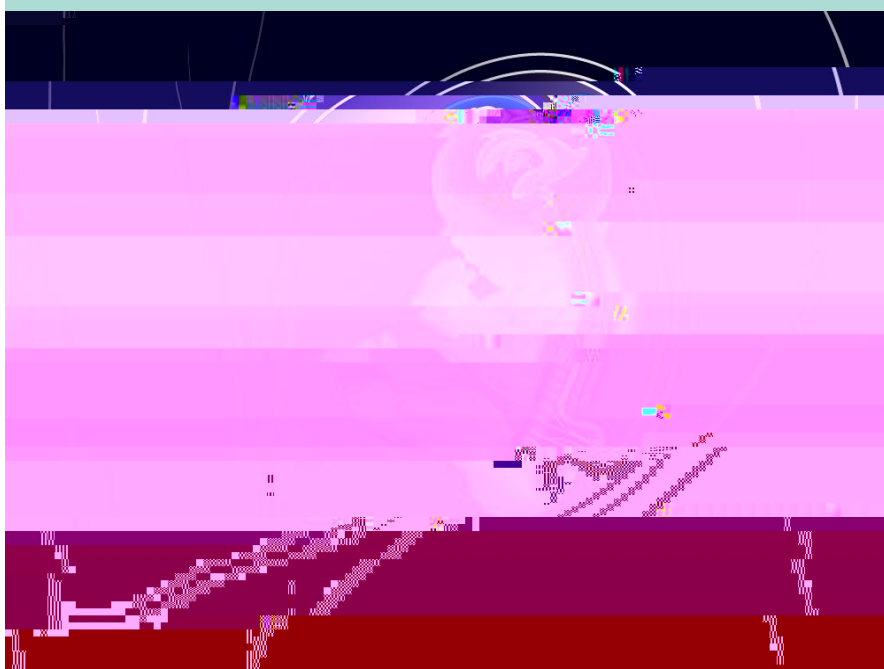


# University College Hospital

## Fetal spina bifida and surgical closure during pregnancy

Information for Pregnant Women & Families









The exact cause is unknown. Several factors may be responsible such as insufficient folate (a B vitamin) in the diet. There are also hereditary factors. Once spina bifida has occurred, there is a slightly increased risk of having a baby with spina bifida again in another pregnancy. Because of this we advise you to take a higher dose of folic acid (5 mg per day instead of the usual 0.4 mg per day) prior to conceiving a next pregnancy. Your doctor should refer you to a genetic specialist (geneticist) if there are several cases of spina bifida in your immediate family.

Every person with spina bifida is unique, meaning there is a large variety of possible effects, from mild to severe. Generally, a defect higher up on the back is associated with more serious consequences. Ultrasound of your baby can be used to

Normally, nerves from the spinal cord go to the muscles of the legs and feet to allow movement. In spina bifida, the spinal cord and nerves are often entirely or partially interrupted at the place of the lesion in the back. This can cause:

- deformity of the spine (also called scoliosis)
- muscle weakness in the legs
- impaired balance
- contracture of several joints
- club feet.

For children with a very low lesion, they are expected to be able to stand and learn to walk or have only mild weakness or deformity in the feet. For lesions at progressively higher parts of the spine, children may have difficulties with walking, or may not be able to walk, stand or even sit.

Because nerve pathways are interrupted in spina bifida, there is less or no sensation in the skin served by nerves below the site of the lesion in the back.0 0 98(b)-3(a)-3(ck.0 0 98(b)-

When hydrocephalus occurs, surgeons often need to implant a shunt. This is a thin tube that drains the fluid from the brain into the abdominal cavity (tummy) of the child. The satisfactory working of the shunt will be assessed from time to time in the out patient clinic. Further surgery to a shunt may be required if there are problems such as infection or blockage. Such shunt complications can be responsible for long term disabilities. Hydrocephalus and complications of drains may result in some learning and behavioural issues.

As many as two thirds of children with spina bifida have an IQ within the normal range. However, children with open spina bifida may have learning and behaviour issues. These include difficulties with concentration, attention and problem solving.

Children with spina bifida often have problems controlling their bladder. This may cause urinary incontinence or inability to fully empty their bladder (referred to as urinary retention). This may lead to bladder and/or kidney infections. To prevent complications, medical staff may recommend that they empty their bladder using a small catheter through the urethra several times a day (called clean intermittent catheterisation). First the parents are taught this, later the children can learn to do it for themselves.

Children also often have bowel issues, resulting in either incontinence or constipation. This can be helped by bowel wash-outs (irrigation) or medication.

Children with spina bifida often have a shorter stature than usual. Early puberty is more common, especially in cases of hydrocephalus.

When young adults with spina bifida are asked about whether they feel happy, their response usually is very similar to their peers. Men with spina bifida may have decreased fertility, but medication usually helps with erection difficulties. Women with spina bifida may have reduced sensation which affects their full enjoyment of sex.



If this is your choice then you will be supported throughout your pregnancy. During the last three months of pregnancy, your child will be monitored by ultrasound, for instance to measure the amount of fluid in the brain. If the fluid increases, sometimes medical staff recommend to deliver your baby a bit earlier. The delivery should be done in a

In a baby with spina bifida, the defect is closed using a similar surgical technique to closure after birth. The womb is then closed and the baby continues to grow and develop in the womb until birth. In 2011, the results of an American study called the "MOMS trial" were published. The study investigated the effect of operating on babies with spina bifida whilst they were still in the womb as compared to operating on babies *after* birth.

Because of the benefits shown in that study, we are offering the opportunity of fetal surgery during pregnancy at University College London Hospital (UCLH) Centre for Prenatal Therapy. Fetal surgery for spina bifida is currently available in only a few places in the US and Europe. UCLH is the first UK centre where fetal surgery is available. Because it is a new treatment in the UK, information on your care during pregnancy and after birth will be collected and reviewed so that we can measure the quality of our care.

In the MOMS study mentioned above, there were 77 children with spina bifida who were operated on in pregnancy, while they were still in the womb. Their outcomes were compared to 80 babies who had s

There are risks of performing the spina bifida closure

At UCLH doctors will repeat the evaluation of your baby by ultrasound and MRI, before the decision can be made to proceed with surgery. This is to make sure that we know as much as possible about the abnormality that your future

If you decide to go ahead with fetal surgery, by law we must ask for your permission and we will ask you to sign a consent form. This confirms that you agree to have the procedure and understand what it involves. Staff will explain all the risks, benefits and alternatives before they ask you to sign a consent form. If you are unsure about any aspect of your proposed treatment, please don't hesitate to speak with a senior member of staff again.

You will be asked to come into hospital after fasting from the night before. You will be shown to a room and given a gown to change into. You will meet the anaesthetist and surgical team again. When you are ready you will be taken into the operating theatre and the anaesthetist offer to insert an epidural catheter (fine plastic tube) into your back for pain relief after the operation. You will then have a general anaesthetic (to put you to sleep). Once you are anaesthetised, a bikini line cut will be made in your abdomen (tummy). This is slightly wider than the size of the cut used for Caesarean section birth, but in the same place on your abdomen. The uterus (womb) is then opened to allow access to the baby. The spina bifida defect is examined and closed by the paediatric neurosurgeon. The uterus and then abdomen are both closed. You will then be woken up.

When you wake up from the operation you may feel a bit sore, but painkillers will be available for you. You will also have an epidural analgesia catheter, through which you can get pain relief. There will be a catheter in your bladder which will be removed once you are able to walk around and pass urine in the toilet.

You will stay in hospital for a period of around one week, and when you go home you will be offered regular follow up and advised to keep relative rest.

If you would like more information about fetal surgery for spina bifida at UCLH please contact us on the following:

Direct line to UCLH Fetal Medicine Unit: 020 3447 9144

Switchboard: 0845 155 5000

Email: [fmumidwife@uclh.nhs.uk](mailto:fmumidwife@uclh.nhs.uk)

You may have many questions following this diagnosis, which can be difficult to remember during consultations. Please write them down so you can discuss them with your doctors.

The internet is a source of a wealth of information, but please be cautious as information found can be confusing and inaccurate. Please ask your doctor for suggested websites.

It may be useful to remember who you have been speaking to in the hospital. You can write those names down on the next page.

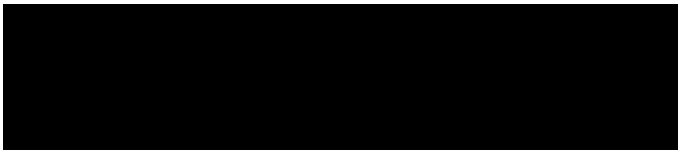
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**Space for your notes:**

This information leaflet is based on the Dutch leaflet “Spina bifida en foetale behandeling tijdens de zwangerschap” which was created with the help of members of the PROSPER consortium (Prospective Spina Bifida Registry of Outcome after Intrauterine Surgery), a national multidisciplinary group of experts involved in the pre- and post-natal care for children with spina bifida.

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Publication date: February 2018  
Date next review due: February 2020  
Leaflet code: UCLH/SHB/WH/FMU/SB/1  
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