



## Great Ormond Street Hospital for Children NHS Trust: Information for Families

# Myelomeningocele

**This leaflet explains about myelomeningocele, what causes it and how it can be treated. It also explains what to expect when your child comes to Great Ormond Street Hospital for assessment and treatment.**

### What is a myelomeningocele?

It is a type of spina bifida.

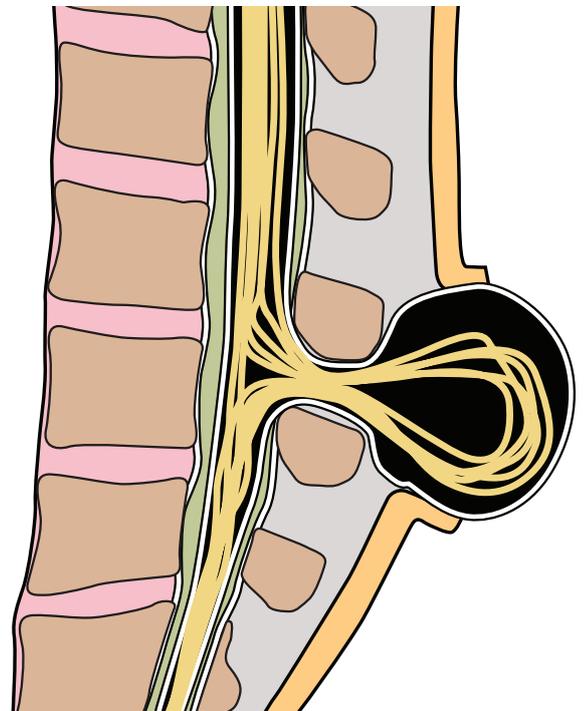
In early development, the brain and spinal cord start as a tube-like structure called the 'neural tube' that is open at either end. These openings close within the first weeks of pregnancy, and the neural tube continues to grow and fold, eventually forming the brain and spinal cord.

If the tube fails to close properly, this results in a group of problems called 'neural tube defects'. There are two types of neural tube defect: open, also called spina bifida aperta or myelomeningocele, or closed, also called spina bifida occulta. This leaflet explains about the open myelomeningocele type, which accounts for 75 per cent of all cases of spina bifida.

In myelomeningocele, the neural tube has failed to close and the neural tissue is exposed at a place on the baby's back called the 'neural placode'. This most commonly happens in the baby's lower back just above the bottom, but could occur anywhere along the spine. The myelomeningocele will look like a sac sticking out from your baby's back.

### What causes myelomeningocele?

We do not really understand what causes neural tube defects in general but we do know that folic acid can reduce the risk of them happening in future pregnancies. More information about this is at the end of this leaflet.



### How is myelomeningocele treated?

Without the protective covering of skin, the spinal cord will become further damaged, spinal fluid often leaks from the area and there is a very high risk of infection. Surgery is usually recommended within the first few days of life. The aim of surgery at this stage is to put the spinal cord back into the spinal canal and repair the defect in the back so that the area is covered with normal, healthy skin.

Before surgery, the affected area is covered with a dressing and your baby will be nursed on his or her front. A number of specialists



will visit to examine your baby, including a neurosurgeon, physiotherapist, paediatrician, orthopaedic surgeon and anaesthetist. After the operation, your baby will be nursed on our neurosurgical ward, still on his or her front for most of the time, although you will be able to feed your baby by breast or bottle and pick up your child as normal.

The physiotherapist will see your child after the operation. He or she will assess how much strength your child has in each muscle group and measure his or her sense of feel. When taken together, muscle strength, sensation and reflexes give us a picture of how well the messages are getting from the brain to the arms and legs via the spinal cord. The physiotherapist will also give advice on how to position and handle your child to stretch out tight muscles and to help with normal development. He or she may also refer your child to local physiotherapy services who can continue to see your child and monitor his or her development. They will also monitor the movement in your child's muscles and joints and may refer him or her to an orthopaedic doctor at your local hospital.

Once your baby is recovering well, you will both be able to go home. We will need you to come back to the ward between 10 and 14 days after the operation so that we can check the operation site, carry out an ultrasound scan of your baby's head and measure his or her head circumference. Four to six weeks afterwards, you will need to come to clinic for a further check up appointment.

## **What problems can myelomeningocele cause?**

There are a number of problems that might face a child born with myelomeningocele. However, we want to emphasise that these vary a great deal from child to child and also may show up at different times during a child's development.

## **Bladder function**

Some degree of bladder problems is the most commonly occurring problem for children with myelomeningocele. However, it is not usually a concern in the first year or so before any baby is potty-trained. Many children with myelomeningocele will fail to develop normal bladder control, but with treatment from a urologist, most children can become 'dry'. Urine infections can be risk for children with myelomeningocele, owing to their bladder control problems. A urologist will usually visit you and your baby soon after birth and tests and investigations will start straightaway. Bowel continence can also be a problem. Medicines and sometimes surgery may be needed in the longer term.

## **Hydrocephalus**

The circulation of cerebrospinal fluid (CSF) is often disturbed in children with myelomeningocele. Either at birth or in the days and weeks following surgery, fluid may start to build up within the brain. This is called hydrocephalus and can result in increased pressure in the brain. If this occurs, an operation to place a shunt tube to divert the excess fluid from the brain to the abdomen is needed. This operation is needed in about 60 per cent of children with myelomeningocele. For more information about hydrocephalus and shunts, please see our leaflet.

## **Arnold Chiari malformation**

This is present in almost all children with myelomeningocele. It mainly involves the lower part of the brain, but the anatomy of the whole brain is affected. Many of the nerves that control the heart, breathing and blood pressure, and help control swallowing, sneezing and coughing can be involved.

When Arnold Chiari malformation is present, the brainstem is elongated and displaced into the opening of the base of the skull and into the top of the spinal canal. It is often kinked. The brainstem, cranial nerves and lower portion of the cerebellum (back of the brain) may be stretched or compressed. This means



that any of the functions controlled by these areas may be affected.

Many people with Arnold Chiari malformation have no obvious symptoms. In babies, the most common symptoms are a weak or absent cry, stridor (noisy breathing), arching of the neck, breathing problems, colour change, failure to thrive and feeding or swallowing difficulties. If any of these symptoms is present, medical advice is needed. Treatment may involve removing a small amount of the bone around the neck and base of the skull to relieve pressure on the brainstem.

### **Mobility**

Myelomeningocele affects each child differently, and how each child moves around will vary too. Some children will need splints or walking aids, and others may move around more easily in a wheelchair. Your consultant will speak to you about how your child's condition will affect their mobility.

### **What is the outlook for children with myelomeningocele?**

The outlook for children with myelomeningocele has improved dramatically in recent decades. Intellectual prognosis is very good for the majority of children, most of whom will go on to full time education. Recreational and employment opportunities are better now than at any time in the past.

In order to fulfil potential and avoid unnecessary complications, your child will need follow up care from a multidisciplinary team throughout childhood. To enable this, your baby will be referred to your local hospital before you leave GOSH. This is important so that a consultant paediatrician and other relevant local teams are involved in your child's ongoing care.

### **What about future pregnancies?**

There is now evidence that an adequate intake of folic acid can dramatically reduce the risk of myelomeningocele occurring in future pregnancies. If you are planning a further pregnancy, we recommend that you take 4mg of folic acid each day for at least three months before conception and for the first three months of pregnancy. This dose is higher than the standard recommendation for women who have not previously had a child with spina bifida. If you have any concerns about future pregnancies, please talk to us as we can arrange a consultation with a genetic specialist for you.

### **Is there a support group?**

SHINE can offer advice and support for parents of children with myelomeningocele. Call them on 01733 555 988 or visit their website at [www.shinecharity.org.uk](http://www.shinecharity.org.uk)

The following are other websites from outside the UK you can visit for further information:

Spina Bifida Association of America  
– [www.sbaa.org](http://www.sbaa.org)

National Institute for Neurological Disorders (NINDS) – [www.ninds.nih.gov/disorders/spina-bifida](http://www.ninds.nih.gov/disorders/spina-bifida)

International Federation for Spina Bifida and Hydrocephalus – [www.ifglobal.org](http://www.ifglobal.org)

Children's Hospital, Los Angeles USA  
– [www.myspinabifidabook.org](http://www.myspinabifidabook.org)

**If you have any questions,  
please telephone Koala Ward  
on 020 7829 8826**