

Spina Bifida Myelomeningocele

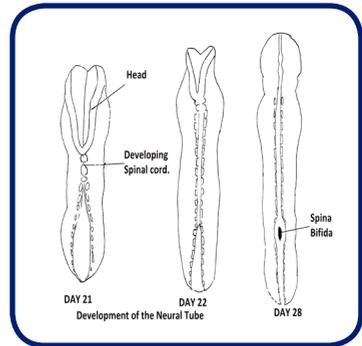
Information for Parents with an
Antenatal Diagnosis of
Spina Bifida-Myelomeningocele



Children's Health Ireland
at Temple Street

What is Spina Bifida?

Spina Bifida is a neural tube defect which is usually noticed on ultrasound during the antenatal scan. The neural tube is a structure which develops in the first month of pregnancy and it forms the brain and spinal cord. When the neural tube doesn't close all the way, the backbone that protects the spinal cord does not form and close as it should. This results in an opening along the spinal cord known as Spina Bifida. The name Spina Bifida means "Split spine" in Latin.



What is a myelomeningocele?

In Myelomeningocele (pronounced my-lo-men-in-jo-seal); the backbone is open and the spinal cord and spinal nerves are exposed. There is usually no skin to cover the opening.

What causes Spina Bifida?

Spina bifida occurs very early in pregnancy (around 25 days). The exact cause of Spina Bifida is not yet known. Genetic, environmental and dietary factors are all likely to play a part. In most cases, it is a random unexplained occurrence. Folic Acid (a B vitamin) can reduce the risk of Spina Bifida. As you have had a pregnancy affected by Spina Bifida we recommend that future pregnancies are planned and that you take 4-5mg of folic acid for at least three months before your next pregnancy and for 3 months afterwards. This is 10 times the normal dose. This higher dose should be taken only when planning a pregnancy. The normal dose of 400mcg should be taken at other times.

How will a myelomeningocele affect my baby?

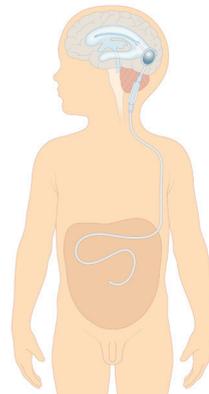
The brain and spinal cord control all our bodily functions. Messages from the brain to our organs and muscles travel through the spinal cord and onwards through nerves. If the spinal cord is damaged or poorly developed, as happens in myelomeningocele, messages or nerve signals cannot travel to and from the affected parts of the body. The location of the myelomeningocele along the spinal cord dictates the nerves that are affected. This is known as the level of lesion. Antenatal ultrasounds and MRI help us establish where this is. Knowing this will help us predict the likely extent of nerve damage and how it may affect your child. Myelomeningoceles that occur high on the spinal cord causes more nerve damage than those located lower.

Effects of a myelomeningocele on the bladder and bowel

Nerves that supply the bladder and bowel come from the lowest (Sacral) area of the spinal cord; therefore all children with Spina Bifida will have problems with their bladder and bowel. Starting toileting programmes (emptying their bladder) in the new-born period can lead to a better outcomes for continence later. The majority of children have a bowel and bladder routine in place and are dry in school.

Hydrocephalus and shunts

Most children (about 85%) with a myelomeningocele will have hydrocephalus, an excess of fluid on the brain. Hydrocephalus is treated by inserting a shunt – this



is a device that drains the extra fluid away from the brain. Children with high level lesions are more likely to need a shunt. The need for a shunt may not be obvious until after the myelomeningocele is surgically closed.

Learning and school

Many children with a myelomeningocele may have specific difficulties with areas of learning such as, reading comprehension, maths, memory, attention and how quickly they can process information. Some children will require additional education support and strategies in mainstream school to help with the aspects of learning that are difficult for them. Every child is different and will have their own specific learning needs.

My Doctor thinks my baby's MRI level of lesion is at _____ . The chart opposite answers frequently asked questions from parents with answers based on the children we have cared for at CHI in Temple Street over the past 10 years.

This is as accurate as we can be at this stage of your pregnancy. However, each child is individual and their abilities may be different than suggested by their MRI level.



Questions Asked by Parents

MRI Functional level of lesion	Will my child walk?	Will my child require a shunt?	Will my child have bowel or bladder difficulties?
Thoracic level T1 to T12	All children were wheelchair users at this level	9 out of 10 did require a shunt	Bowel and bladder of all children were affected
Lumbar level L1 and L2	All children were wheelchair users at this level	10 out of 10 did require a shunt	Bowel and bladder of all children were affected
Lumber level L3	8 out of 10 children were wheelchair users at this level	9 out of 10 did require a shunt	Bowel and bladder of all children were affected
Lumbar level L4	5 out of 10 children could walk at this level	7 out of 10 did require a shunt	Bowel and bladder of all children were affected
Lumbar Level L5	3 out of 4 children could walk at this level	7 out of 10 did require a shunt	Bowel and bladder of all children were affected
Sacral	9 out of 10 children would walk at this level	6 out of 10 did require a shunt	Bowel and bladder of all children were affected

If I choose to continue my pregnancy what are my surgical options for my baby?

Surgery during pregnancy

Surgery to close or cover the myelomeningocele before birth can be carried out in certain circumstances. There are significant risks to the mother and her unborn baby. The surgery needs to be performed before 26 weeks of pregnancy. Several tests need to be done before hand. The surgery, which is now available in the UK and some centres in Europe, will accept referrals from Ireland. The cost of treatment will be met by the HSE Treatment Abroad Scheme.

Potential benefits of foetal surgery for your baby:

- Less need for a shunt for hydrocephalus by the age of one year.
- Less severe Arnold Chiari 2 Malformation (hindbrain herniation)
- Better leg function at 30 months of age

information obtained from www.uclh.nhs.uk

Surgical closure after my baby is born

After birth your baby will be assessed by the multidisciplinary team in CHI Temple Street, your baby's condition will be discussed with you. The timing of your baby's surgery will depend on this discussion. The surgery to close the myelomeningocele on your baby's back normally occurs within 48 hours of birth. This surgery will not change nerve damage that has already occurred and there will be no improvement in nerve function following the operation. The myelomeningocele must be closed to reduce the risk of infection to the brain and nervous system and to make it easier to care for your baby in the usual way.

What if I have concern's regarding my pregnancy; who can I talk to?

Please feel free to contact our Spina Bifida Nurse Specialist Team if you have any questions about anything relating to your baby's diagnosis on 01-8921768.

or

Foetal Assessment Unit National Maternity Hospital Holles Steet, 01 6373217 If you have any questions about your pregnancy.

Other Useful Supports

www.spinab.ie

Spina Bifida Hydrocephalus Ireland Lo-call 1890 20 22 60

www.sbhi.ie

Glossary

Arnold Chiari Malformation: A condition in which the brainstem has dropped lower towards the spinal cord than usual.

Backbone: Bones of the spine.

Bowel: Last part of the digestive system.

Thoracic Area: Bones of the spine within the chest area.

Lumbar Area: Bones of the spine in the lower back.

Sacral Area: Triangular bone (sacrum) at the bottom of the spine. You sit on this part of the spine.

MRI: A magnetic scan.

Neural Tube: Embryonic cells that develop brain and spinal cord.

Spinal Nerves: Nerves that carry messages to and from the brain to different parts of the body. They branch out from the spinal cord at regular intervals.

Spinal Cord: Contains the spinal nerves and is protected by the bones of the spine. It is a continuation of the brain.

Authors: Ciara O'Prey
Orla Mc Mahon
Francis Keegan
Sandra Hayes
Regina Mc Crann

Version: 1

Approval Date: July 2019

Review Date: July 2022

Copyright © Children's Health Ireland at Temple Street