

# Myelomeningocele

Myelomeningocele occurs when part of the spinal cord sticks out (protrudes) through your child's back. This is a serious birth defect that causes permanent neurologic abnormalities. The type and severity of your child's handicaps depend on where the myelomeningocele is located. Children with myelomeningocele need lifelong follow-up care from a team of health care specialists.

## What is myelomeningocele?

Myelomeningocele is one of a group of birth defects called "neural tube defects," in which the spinal cord doesn't close normally as the fetus is developing. In babies with myelomeningocele, part of the spinal cord sticks out through the back. Most myelomeningoceles are located in the lower back, but they can occur anywhere along the spine.

Myelomeningocele usually causes some permanent damage to the spinal cord and may result in many different medical problems. Problems with bowel and bladder control are common. Surgery is done to close the spinal cord within a few days after birth; additional evaluation and treatment are provided by a team of health care professionals. Although this is a serious birth defect, most children with myelomeningocele have normal intelligence and at least some walking ability.

A "meningocele" is different from a myelomeningocele. It is an outpouching or pocket of just the membranes covering the spinal column, not the spinal cord itself. This is a much less serious condition.

## What does it look like?

- Myelomeningocele is obvious at birth. Part of the spinal cord is seen sticking out of your child's spine, often covered by a thin layer of skin.
- Three fourths of myelomeningoceles are located in the lower back. However, they may be located anywhere along the spine, from the tailbone to the neck.
- Many different medical problems may be present. All children with myelomeningocele have some nervous system abnormalities caused by damage to the spinal cord. Myelomeningoceles located higher on the spinal cord (except in the neck or high upper back) cause more severe and widespread abnormalities. However, even low defects cause significant handicaps.
- Many children with myelomeningocele have some weakness and difficulties controlling the muscles in the lower body. This usually means lifelong problems related to bowel and bladder control and walking ability, depending on where the defect is and how much spinal damage is present.

- Children often may not be able to feel pain or feel being touched in the parts of the body affected.
- Many children with myelomeningocele have a problem called *hydrocephalus*, in which fluid builds up in the skull, placing abnormally high pressure on the brain. *Treatment is needed to prevent brain damage or death.* 
- Other birth defects related to spinal cord damage may be present, such as clubfoot or dislocated hip.
- Most children have normal intelligence, but the risk of learning disabilities and seizure disorders (epilepsy) is increased.
- *Every child with myelomeningocele is different.* Several different factors affect the severity of your child's handicaps and medical problems. Your medical team can give you detailed information about your child's condition after a thorough medical evaluation.

## What causes myelomeningocele?

The exact cause is unknown. However, many different factors probably play a role in causing myelomeningocele, including genetics. (See below.)

## What puts your child at risk of myelomeningocele?

If you've had a child with myelomeningocele, future children are at increased risk of the same birth defect.

Other risk factors include:

- Low levels of folic acid in the mother during pregnancy.
- Taking certain medications during pregnancy, including some drugs for epilepsy.

## Can myelomeningocele be prevented?

For mothers, getting enough folic acid (vitamin B<sub>6</sub>) during pregnancy reduces the risk of myelomeningocele and other neural tube defects. The recommended dose is at least 400 micrograms (mcg) per day. This is especially important for women who have had a child with one of these birth defects or for women taking drugs to treat epilepsy. In these cases, the recommended dose is higher.

## How is myelomeningocele treated?

Myelomeningocele is a serious condition requiring a team approach to treatment. Several different doctors and other health professionals play a role in planning and carrying out your infant's treatment. Our office will continue to coordinate your baby's care.

- *Surgery* is needed to cover the exposed portion of your baby's spinal column. This operation may be performed a few days after birth if your infant's medical condition is stable.
- If *hydrocephalus* is present, surgery is usually needed to remove fluid buildup that is placing excessive pressure on the brain. A device called a shunt may be placed to drain fluid away from the skull. Excess fluid drains through a thin tube, usually emptying into the abdomen, where it is absorbed. Shunts can sometimes have problems, such as infection or malfunction.
- *Additional operations* or other treatments may be needed for other deformities that may accompany myelomeningocele, such as clubfoot or dislocated hip.

### What are the long-term issues in care for myelomeningocele?

Because of spinal cord damage, children with myelomeningocele don't have normal control over the muscles of the lower body. This leads to problems with controlling bladder and bowel function and with walking ability. The severity of these problems depends on the location and severity of the spinal cord damage.

- *Bladder control.* Children with myelomeningocele may have bladder problems (neurogenic bladder). Most are unable to contain their urine (incontinence); for others, the bladder does not empty completely. Parents may have to learn to perform regular tube drainage (catheterization) of the bladder. As children get older, they can learn to do this on their own. Certain medications may also help with bladder control.
- Surgery is usually needed only if catheterization and medications are not enough to achieve bladder control. All children need long-term medical follow-up to prevent kidney damage.
- *Bowel control.* Lack of bowel control becomes a problem after your child reaches the normal age for toilet training. When the time is right, many children can undergo bowel training, using enemas or suppositories at certain times of day.
- *Walking ability.* Assessment and treatment focus on maximizing the function of your child's legs. Nearly all children whose myelomeningocele is located in the lower spine can get around independently. Even for many of these with damage higher in the spine, walking is possible with aids such as braces or canes.
- *School and long-term function.* Most children with myelomeningocele have normal intelligence. Some have different degrees of developmental problems, such as learning disabilities. Special education services are available in every state. You are entitled to evaluation and educational services for your child. Based on the results, an Individualized Education Program (IEP) can be developed to meet your child's educational needs.
- *Long-term medical care.* Myelomeningocele is often a chronic, handicapping condition. Your child will need lifelong medical care. With good health care and support, many people born with myelomeningocele lead productive, relatively normal lives.
- *Taking care of your family.* Having a child with a serious birth defect is a traumatic event that affects your family in many ways. Doctors and other health care professionals can provide you with the information you need to understand your child's specific situation and the necessary treatments. Counseling may be helpful in helping your child and family deal with the stresses of living with a child with a chronic disease.



### When should I call your office?

Call our office if you need additional information on myelomeningocele and your child's medical care.