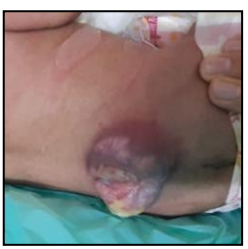
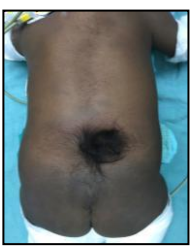
Patient Information Sheet

SPINA BIFIDA MENINGOMYELOCELE





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What is spina bifida/meningomyelocele ?

Spina bifida is a birth defect of the spinal cord. It can be obvious or hidden (occulta).

Meningomyelocele (MMC), is an obvious spina bifida. In this condition the spinal cord (nerves) with its coverings bulges through a defect in the back-bone producing a translucent swelling on the back. If only the coverings are out it is called meningocele and if the entire spinal cord is open then it is called myelocele,

In the occulta variety there are tell-tale signs eg a patch of hair or a pit or a discoloured patch of skin instead of the classical swelling.

What causes the problem and how common is it ?

This problem is a result of defective development of the back bone and occurs early in pregnancy. The nerves of the spinal cord bulge out of this defect and lie exposed. This causes injury and damage to nerves and hence the part of the body these nerves supply become weak. For every 1000 babies born in India, 8 or 9 may have this condition, which is a big number. One known reason for this disease is deficiency of the vitamin called folic acid.

What are the symptoms ?

Most commonly this affects the lower back. So, the common symptoms are weakness of the legs and loss of proper control of urination and stool evacuation. Though the doctor can easily pick up these deficits, parents may not be able to observe these issues in the newborn. Some may also have a big head (hydrocephalus).

When to see your doctor ?

Most pregnant women nowadays undergo antenatal ultrasound scan, especially the anomaly scan during second trimester. Spina bifida can be detected when this scan is done. When in doubt the doctor may recommend further testing by foetal MRI scan. It is then important that the prospective parents consult a pediatric surgeon for further counselling and guidance. Sometimes, the defect goes undetected till birth of

the baby. In such cases, the pediatrician will immediately get a pediatric surgeon involved.

In the rare case of spina bifida occulta, a growing child may develop gradual weakness of legs, abnormal gait, loss of urine control, back pain, etc. Parents must then consult a pediatric surgeon.

How is it diagnosed ?

MRI of the spine and brain will confirm the diagnosis. Sometimes the doctor will advise a CT scan of the spine also. An ultrasound abdomen is done to evaluate the child's kidneys and bladder. Rarely the surgeon may recommend special tests to detect pressure of urinary bladder and function of kidneys.

What are the treatments available ?

Treatment is multipronged and continues through childhood and adolescence. It is both surgical and medical. Surgery of the back is usually done in infancy itself, but some children may also need orthopaedic surgery or casts for stiff ankles. Some may need a tube to be placed in the brain to remove excess fluid that's accumulated there. Children are prone to urinary infections and kidney damage in the long term and need monitoring for the same. In an effort to keep them dry and clean parents are taught to empty the child's bladder using a tube and completely evacuate bowel using enemas.

Are there any alternatives to surgery ?

If detected very early in pregnancy, and the prognosis is bad, prospective parents have the option of terminating the pregnancy (prior to 24 weeks gestation). Also it is important that prospective mother is given folic acid supplementation even before pregnancy is planned.

What does the operation involve ?

The operation involves repositioning the exposed nerves back within the back bone and covering it with protective layers (called dura, muscle and skin). In children with associated large head called hydrocephalus, a shunt tube (tube draining excess brain fluid into abdominal cavity) is also performed.

What are the possible complications / what happens after the operation ?

There may be a leak of fluid (called CSF, that is seen around brain and spinal cord) from the operated site on the back. If a tube is placed in the brain cavity, this may get blocked. Baby may have fits secondary to surgery or its complications.

What is the outlook or future of these children ?

This is a disease that requires life-long care and monitoring. If parents and children are guided well through the challenges of using catheters (tubes) for urine and stool management, physiotherapy and callipers if needed, for gait support, the quality of life can be acceptable.