Myelomeningocele

Myelomeningocele happens when a baby is in the womb. It is a type of spina bifida. It is a problem where the spinal column and vertebrae are not formed right in the womb. When the spinal cord is forming, it normally starts out shaped like an open tube. This tube slowly closes from top to bottom. When this tube does not close all the way, problems like myelomeningocele happen. It causes a sac containing spinal cord nerves, the covering of the spinal cord, and spinal fluid to stick out of the back at birth.

CAUSES

We do not know the exact cause of myelomeningocele. However, having one child with this problem increases the risk in future pregnancies.

SYMPTOMS

Babies are born with a fluid-filled sac sticking out of the back. Other symptoms depend on where in the back the problem exists. Symptoms can include:

- Loss of bladder or bowel control. This can cause urine or bowel leaking. Sometimes there can be constipation or inability to pass stool.
- Lack of feeling in body parts below the problem.
- Partially or completely unable to move the legs (*paralysis*). This can cause difficulties or the inability to crawl or walk.
- Joint problems. This is mostly noticed in the hips, knees and feet. Joint issues can cause deformities or problems with normal function of the joints.
- Fluid and pressure build-up in the skull due to poor drainage of the spinal fluid.

Most children with this problem have normal intelligence. They can live a normal life span with the right care.

DIAGNOSIS

Myelomeningocele can be diagnosed before birth. Caregivers use screening blood tests and an ultrasound of the fetus.

TREATMENT

There is no cure for myelomeningocele. There are many treatments available for associated problems. Usually, a team of caregivers are needed to address all the issues.

- Surgery is often performed first. Surgery will close the opening in the back to stop infection. Often, another surgery is done to place a tube called a VP shunt *(ventriculoperitoneal shunt*) from the brain to the abdomen. This tube prevents the build-up of fluid and pressure in the skull (*hydrocephalus*) due to lack of normal drainage of the spinal fluid.
- Evaluation of the muscles, joints, bones, urinary tract system, nervous system and intestines are important. Orthopedic (muscles, joints and bones) problems with the knees, feet, hips or back may need treatment right away and careful following over time. Corrective surgery and bracing is often needed for leg problems. A curved spine may need treatment.
- Loss of feeling in the buttocks and legs can lead to injury. To prevent this, careful attention to bath water temperature and other heat sources is important. Careful skin care and watching for redness or sores should be done.
- Most children with myelomeningocele have bladders that do not work right. This leads to urine leakage, urine back flow into the kidneys, and urinary tract infections. Medications, surgery and putting a tube in the bladder to help empty urine (*bladder catheterization*) are helpful treatments. Kidney and bladder function need regular testing.
- Constipation and stool leakage can be treated with diet, medicines and putting fluid into the rectum (*enema*).
- Muscle jerking or shaking (*convulsions*) can happen in some children. This is treated with medications.

HOME CARE INSTRUCTIONS

The parents are an important part of the team of caregivers. Treatments for urine, orthopedic and bowel problems will need to continue at home. These will be directed by the caregiver team.

Families are often stressed by their child being diagnosed with this condition and all the ongoing treatments and surgeries. Support groups and counseling are useful in helping families work through the issues. Looking to friends and families for support is also a good idea.

SEEK MEDICAL CARE IF:

- Your child shows signs of increased fluid and pressure build-up due to blockage of the VP shunt.
  - Headaches.
  - Personality changes.
  - Poor school performance.
  - Throwing up (*vomiting*).
- Your child shows signs of problems around the spinal cord surgery area.
  - Change in walking.
  - Loss of strength.
  - Unusual stiffness in legs.
  - Change in bowel or bladder function.
  - Pain in the surgery area.
  - Worsening tiredness (*fatigue*) in the legs.
  - Increase in any curvature of the spine
- You suspect your child is having convulsions, look for:
  - Rhythmic jerking or twitching of the arms or legs.
  - Sudden falls for no reason.
  - Lack of response or dazed behavior for brief periods.
  - Staring or rapid blinking.
  - Unusual sleepiness or irritability when waking.

SEEK IMMEDIATE MEDICAL CARE IF:

- Your infant shows signs of increased fluid and pressure build up due to blockage of the VP shunt.
  - Bulging soft spot.
  - Increasing head size.
  - Irritability.
  - Poor feeding.
  - Feeling sleepy all the time.
  - Throwing up (*vomiting*).
- Your infant shows signs of increased pressure build-up at the base of the brain.
  - Squeaky, labored inhaling.
  - Choking with food.
  - Hoarseness or lack of a voice.
  - Shallow breathing or periods where breathing stops.
- There are signs of infection of the shunt, which would be any of the signs of increased pressure plus a fever.
- A convulsion lasts more than 5 minutes, is unusual in some way or breathing trouble follows.

MAKE SURE YOU:

- Understand these instructions.
- Will watch your condition.
- Will get help right away if you are not doing well or get worse.

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