



Kids Brain Doc

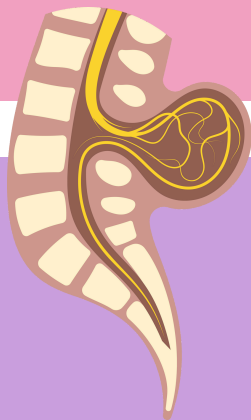
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Myelomeningocele

Patient Packet



Diagnosis: Myelomeningocele



What is it?

It's a type of spina bifida, where part of the spinal cord and nerves develop outside the baby's back in a fluid-filled sac. It is a condition that affects how the spine and spinal cord formed during early pregnancy.

Who does it affect?

It affects babies during fetal development, and is usually diagnosed before birth or at delivery. It can happen in any pregnancy.



How did my child get it?

It develops early in pregnancy when the spine doesn't close all the way. The exact cause isn't always known, but it may be related to low folic acid levels, genetics, or other environmental factors.



Is it Harmful?

It can affect your baby's movement, bladder and bowel function, and brain development, but every child is different. Early treatment and ongoing care can help your child live a fulfilling and meaningful life.



What is the Treatment?

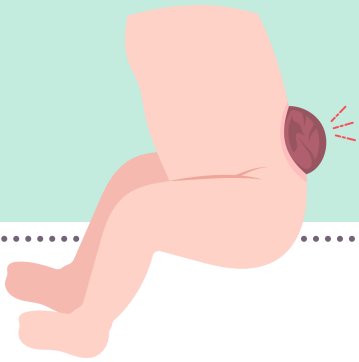
Most babies will need surgery within 1-2 days after birth to close the opening in the back and protect the spinal cord. Some children may also need additional care for hydrocephalus (fluid buildup in the brain), walking support, and bladder or bowel management as they grow.



Surgery: Myelomeningocele Repair

1 Goals of Surgery

- Protect exposed spinal cord and nerves
- Prevent infection and further injury to the spinal cord



4 Right after Surgery

- Your baby will be admitted to the NICU with a foley (catheter in the bladder)
- They will lay on their stomach or side for several days for their back to heal
- Pain medications: IV Tylenol, IV morphine.
- Antibiotics: 24 hours
- Weekly head ultrasound

2 Risks of Surgery

- Infection, bleeding, or wound breakdown. We will start antibiotics for your baby as soon as they are born
- Injury to normal nerve roots or worsening function
- CSF (Cerebrospinal fluid) leak: this may be a sign that your child has hydrocephalus, which also needs surgery (VP Shunt)

3 Alternatives

- Surgery is the standard treatment (either when you are pregnant or after the child is born)
- Delaying surgery increases the risks of infection and complications

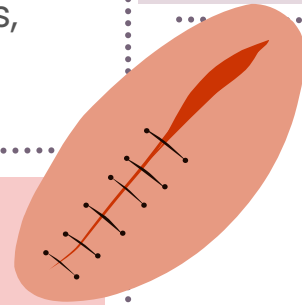
5 Hospital Recovery

Once the incision on the back is healed, there are no signs of pressure on the brain, and the NICU has no further concerns, your baby may go home with you.

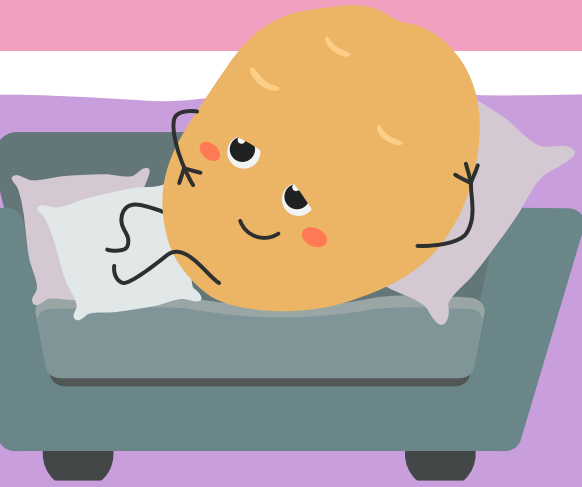


6 Incision Care

- Ok to shower 2 days after surgery. Wash your baby daily
- No bathing or soaking incision in tub for 4 weeks after surgery
- Incision will fall off on it's own in 3-4 weeks
- No need to cover the incision



Recovery & Follow-Up



ACTIVITY RESTRICTIONS

- Week 0-2: Baby should be on their side or tummy to protect the incision
- 1-3 months: begin gentle tummy time, ok to start physical therapy
- At 3-months: Clear for all activities

HOME CARE

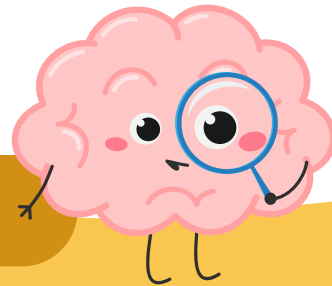
Will see in clinic for incision check at 2 weeks. Continue to follow instructions for their bladder.

FOLLOW-UP

- 2-week: incision check
- 6-weeks
- 3 months
- Annual check-up



LONG-TERM CARE



- Regular neurosurgery visits to monitor for hydrocephalus, tethered cord, or spine changes.
- Bladder and bowel care will be coordinated with urology and GI specialists as your child grows.
- Developmental and mobility support through physical therapy, orthopedics, and early intervention services.
- Recourses: Spina Bifida Association (SBA)