

**Kids Brain Doc**

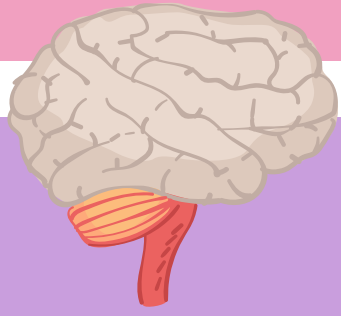
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# Occipital Encephalocele

## Patient Packet



# Diagnosis: Occipital Encephalocele



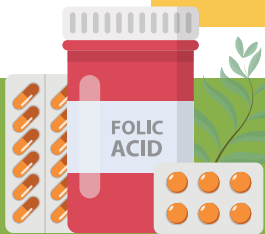
## What is it?

A birth defect where a pouch containing brain tissue, spinal fluid, and protective membranes pushes through an opening in the skull at the back of the head.



## Who does it affect?

It affects babies while they are developing in the womb and is usually identified before birth or during delivery. It can occur in any pregnancy.

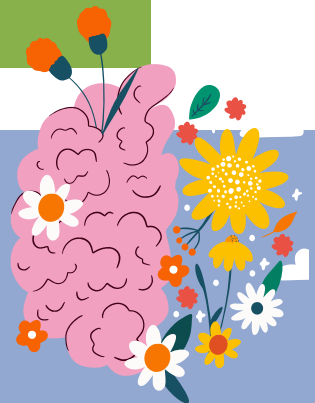


## How did my child get it?

It starts early in pregnancy when the spine doesn't fully close. The exact cause isn't always clear, but it might be linked to low folic acid, genetics, or other environmental reasons.

## Is it Harmful?

It can affect brain growth and development, depending on the size and contents of the sac. Early treatment and ongoing care can help your child live a fulfilling and meaningful life.



## What is the Treatment?

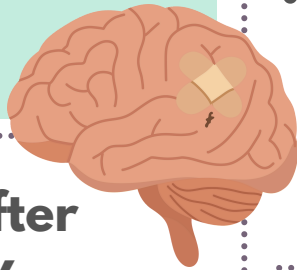
Most newborns will need surgery 1-2 days after birth to close the skull opening and protect the brain. Some kids might also need extra help for fluid buildup in the brain, known as *hydrocephalus*, with a VP Shunt.



# Surgery: Encephalocele Repair

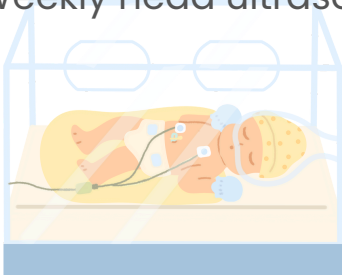
## 1 Goals of Surgery

- Repair the skull and remove brain tissue that grew outside the skull
- Protect the brain from further injury and infection
- Improve the head shape



## 4 Right after Surgery

- Your baby will be admitted to the NICU
- 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 brain tissue or worsening function
- CSF (Cerebrospinal fluid) leak: this may be a sign that your child has hydrocephalus, which also needs surgery (VP Shunt)

## 5 Hospital Recovery

Once the incision on the head 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.



## 3 Alternatives

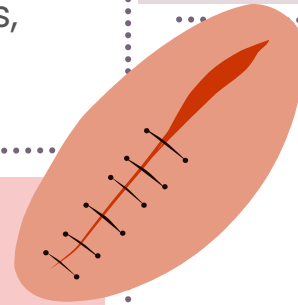
- Surgery is the standard treatment
- Delaying surgery increases the risks of infection and complications



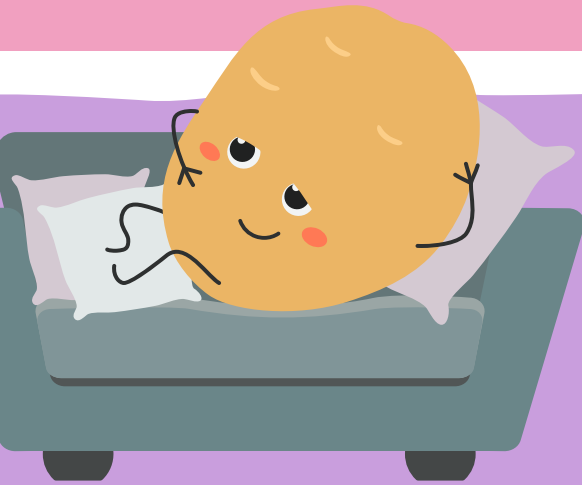
## 6

### 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

- It's important to see the neurosurgeon regularly to check for hydrocephalus.
- Some children may need continued therapies like physical, occupational, or speech therapy, depending on how their brain was affected by the encephalocele.
- If there are concerns about seizures or managing muscle tone, we can refer you to a neurologist.
- Most children do really well, but their long-term outcomes can differ based on the encephalocele's size and location.

