



Kids Brain Doc

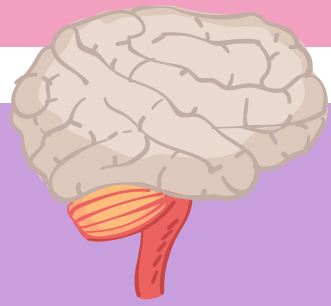
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Chiari 1 Malformation

Patient Packet



Diagnosis: Chiari 1 Malformation



What is it?

Did you know that just like tonsils in your throat, your lower part of your brain (cerebellum) also has tonsils? And when these tonsils slip down the opening at the base of your skull, they can put pressure on your brainstem and spinal cord!

Who does it affect?

It affects 1% of the population, but only 0.1% show symptoms. It's more common in females.

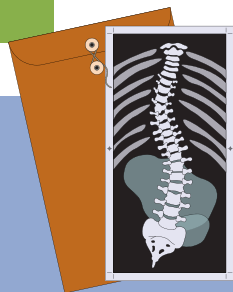


How did my child get it?

Typically congenital (present at birth) and linked to complex genetics. Sometimes caused by spinal fluid leaks from injury, toxins, or infection.

Is it Harmful?

Usually not, unless you are having symptoms or a syrinx (fluid filled pocket in spinal cord). A syrinx occurs in 20-75% of cases and can cause scoliosis. Other symptoms include repeated headaches in the back of the head, issues with swallowing, sleep apnea, and many more.



What is the Treatment?

If there are no symptoms, we just observe it. It may even resolve with time. If you have symptoms or a syrinx, you need surgery (Chiari Decompression).



Surgery: Chiari Decompression

1 Goals of Surgery

- Allow for normal Cerebral spinal fluid (CSF) flow around the brainstem/spinal cord
- This is done by creating more room in the posterior fossa and foramen magnum to relieve the hindbrain compression

2 Risks of Surgery

- Risks from the bone removal portion: Infection, bleeding, wound not healing, need for repeat surgery, and headaches
- If also receiving duraplasty: Injury to the brain/blood vessels, CSF leak, fluid collection to back of head, meningitis, and seizures

3 Alternatives

Types of surgery:

- Remove only the bone over the coverings of the brain (Suboccipital craniectomy and C1 laminectomy)
- ± Expand the covering of the brain (duraplasty)

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Right after Surgery

- Your child may be hesitant to turn their neck because it feels sore. They may also feel nauseous and complain of a headache.
- Pain medications: IV Tylenol, IV Toradol, Muscle relaxant
- If duraplasty: Steroids x3 days
- Antibiotics: 24 hours



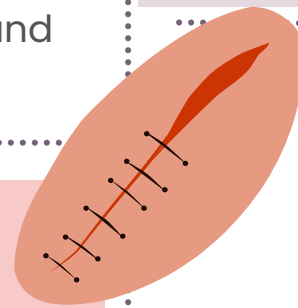
5 Hospital Recovery

- Once your child is taking all their medicine by mouth, eating/drinking, peeing, and moving ok, your child can go home

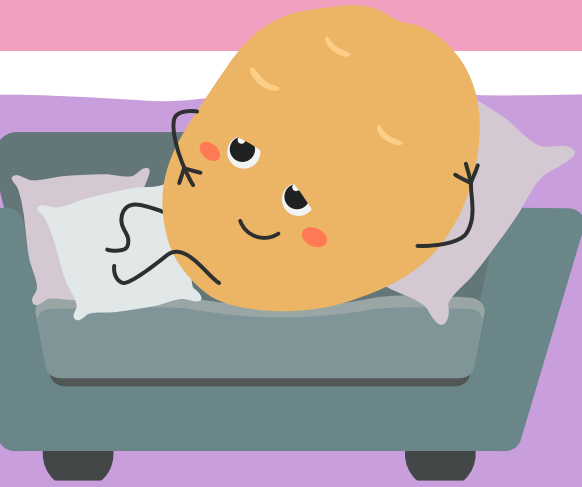
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Incision Care

- Ok to shower 2 days after surgery. Wash 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: Couch potato
- Week 0-4: Light activity
- 1-3 months: Regular activity (keeping two feet on the ground – avoid jumping)
- At 3-months: Clear for all activities

HOME CARE

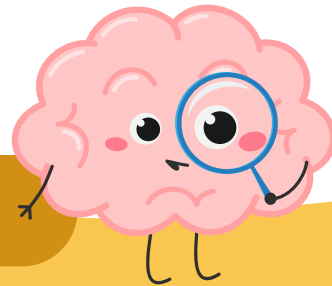
Will see in clinic for incision check at 2 weeks.
Can return to school or daycare after this appointment.

FOLLOW-UP

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



LONG-TERM CARE



- Return to sports: After 3 months, ok to return to non-contact sports
 - Avoid activities that may strain the neck, like heavy lifting, gymnastics, or contact sports (more detailed discussions in clinic)
- Annual eye exams to rule out pressure build up in the optic nerve (*papilledema*) that could indicate increased pressure in the brain
- May need to continue to see a neurologist or pain specialist for pain management.