

**Kids Brain Doc**

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# Chiari 1 Malformation

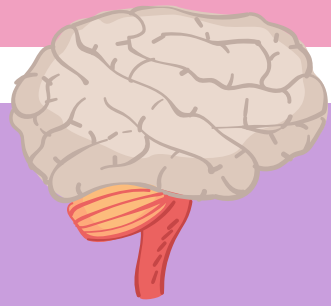
## Patient Packet



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# Diagnosis: Chiari 1 Malformation



## What is it?

Did you know that just like tonsils in your throat, the 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.

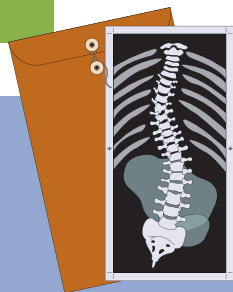


## How did my child get it?

Typically present at birth (*congenital*) 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 fluid-filled pocket in the spinal cord (*syrinx*). 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).



# Follow-Up (if no surgery needed)



## ACTIVITY RESTRICTIONS

- Most children can participate in normal activities, without activity restrictions
- If new symptoms occur during an activity (headaches, weakness, numbness), stop the activity and contact your neurosurgeon.

## HOME CARE

Encourage regular sleep, hydration, and healthy exercise. Keep track of any headaches or new symptoms.

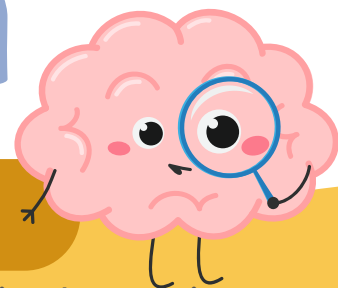
## FOLLOW-UP

Your doctor may recommend follow-up visits and repeat imaging if symptoms worsen or new symptoms develop.



## LONG-TERM CARE

- Schedule 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/headache management.
- Most children live normal, healthy lives
- Ongoing care usually means routine check-ins with your neurosurgeon or pediatrician, especially if new concerns arise



# 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

## 4 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 for 3 days
- Antibiotics: 24 hours



## 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 the back of the head, meningitis, and seizures

## 5 Hospital Recovery

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



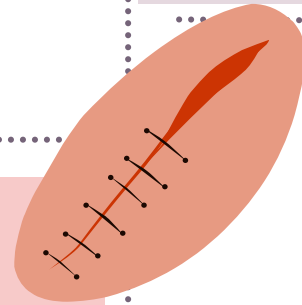
## 3 Alternatives

Types of surgery:

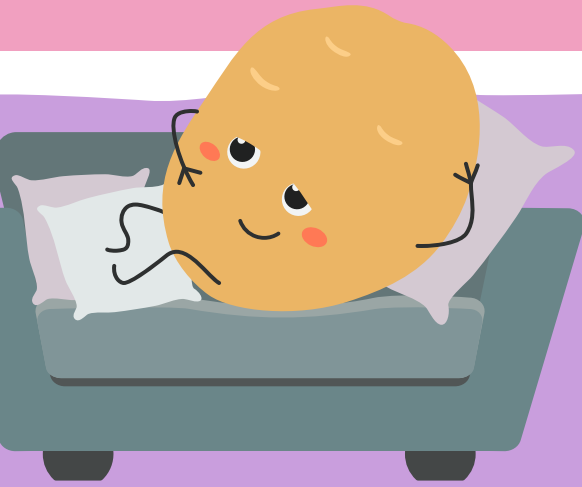
- Remove only the bone over the coverings of the brain (*Suboccipital craniectomy and C1 laminectomy*)
- ± Expand the covering of the brain (*duraplasty*)

## 6 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 its 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

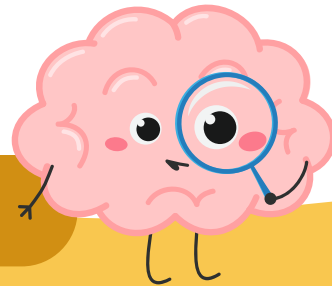
Will see in clinic for incision check at 2 weeks.  
Can return to school or daycare after this appointment.

## FOLLOW-UP

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



## LONG-TERM CARE



- Return to sports: After 3 months, it's okay to return to non-contact sports.
  - Avoid activities that may strain the neck, like heavy lifting, gymnastics, or contact sports (more detailed discussions in the clinic).
- Schedule 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/headache management.