



This family education sheet explains what Chiari malformation, the treatment options for Chiari malformation type I (CMI).

Does my child need treatment?

- Treatment isn't always needed.
- In some cases, medical or surgical care is important to prevent complications and improve someone's quality of life.

When is treatment usually *not* needed?

Your child has mild symptoms or no symptoms

- In this case, the CMI was probably found on MRI (during a scan for other issues).

Mild, stable symptoms

- Occasional headaches or neck discomfort
- No neurological problems
- No impact on your child's daily life

Monitoring plan

- Regular check-ups and MRIs
- Pain management as needed
- Changing activities

When should treatment be considered?

Symptoms are getting worse over time

- Numbness, tingling or weakness in the arms or legs
- Trouble with balance or coordination
- A hard time with small movements, like writing or buttoning clothes

Intense headaches at the back of your child's head that affect their quality of life

- Can be triggered by coughing, laughing or straining
- Headaches may happen without these activities.

Brainstem or cranial nerve symptoms

- Trouble swallowing
- Severe central sleep apnea (found during a sleep study)
- Hoarseness, gag reflex changes

Syringomyelia (syrinx) on an MRI

- This means there's a pocket of fluid inside the spinal cord.
- It can sometimes press on nerves and cause problems like weakness, numbness or curvature of the spine (scoliosis).

Worsening over time

- Symptoms are happening more often or getting worse over time.
- New symptoms are developing over months or years. This may be normal, but you should talk to your child's doctor to be sure.

What are treatment options?

Non-surgical

- Pain medications
- Physical therapy
- Lifestyle changes

Surgery (if needed)

- Posterior fossa decompression – the most common surgery for CMI
- Goal – get rid of pressure and restore normal cerebrospinal fluid (CSF) flow

Surgical vs. non-surgical treatment

We may recommend watching and waiting if your child's MRI doesn't show fluid buildup in the brain (hydrocephalus) or spinal cord and their symptoms are mild (just headaches now and then).

Surgery may be an option if your child has a lot of intense headaches, balance or swallowing problems or fluid collecting in the spinal cord.

When should we get care right away?

Your child needs care right away if they have:

- Sudden numbness or weakness
- Loss of coordination or having a hard time walking
- Incontinence (bladder or bowel control issues)
- Fainting or breathing problems

When should I call the doctor?

Call if:

- You notice new or symptoms or symptoms get worse
- You want to talk about the possibility of surgery
- Your child's symptoms are impacting their life

Resources

- Conquer Chiari: conquerchiari.org
- Talk with a neurologist or neurosurgeon who has experience treating children with CMI.

This family education sheet is available in Spanish.