



Chiari Malformation Type I

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This family education sheet explains what Chiari malformation type I (CMI) is.

Key points

- CMI is when part of the brain pushes through the opening at the bottom of the skull.
- It's a common condition and doesn't always need treatment.
- How it affects each person can vary a lot.

What is CMI?

- CMI is when a lower part of the brain, called the cerebellar tonsils, extends into the spinal canal.
- Normally, the brain sits completely within the skull. But in CMI, part of the brain pushes through the opening at the bottom of the skull (called the foramen magnum). This can create pressure and block the flow of cerebrospinal fluid (CSF) (see Figure 1.)
- CMI is common in children.
- Symptoms are often mild. Many children don't have any symptoms.
- It's often discovered when a child has imaging tests for a different reason, like for a concussion. It's not life-threatening.

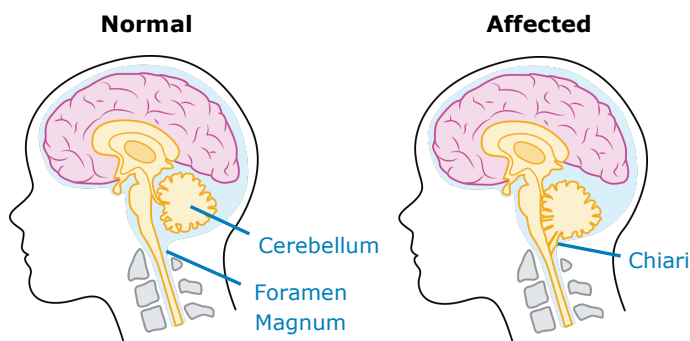


Figure 1.

What causes CMI?

- Children are born with the condition (congenital).
- It may be related to having an underdeveloped skull.
- It can be associated with other conditions, like syringomyelia, scoliosis or Ehlers-Danlos syndrome.
- Chiari is caused by a structural growth abnormality. It's usually caused by genetic changes (a genetic "mutation") that your child inherits from a biological family member. Or it can happen randomly while a

fetus develops. In rare cases, CMI can develop after birth, but this is due to other neurological conditions that affect the brain and spinal cord.

- In CMI, the section of the skull that holds the cerebellum is smaller than usual.
- This causes the cerebellum to push into a different place than is expected.
- The cerebellum moves downward, where there's extra space in the opening at the base of the skull, called the foramen magnum.
- You may hear doctors referring to the "descent" or "herniation" of a specific part of the cerebellum called the "tonsils" into the foramen magnum.
- These "tonsils" aren't the same as tonsils in the throat – they're very different structures! This means that part of your child's brain protrudes, or "descends", into an area of the skull where it normally doesn't belong.

What are the signs and symptoms?

How it affects each person can vary a lot. Many children don't have any symptoms. If your child has symptoms, they may include:

Headaches

- Often at the back of the head (occipital region)
- Can worsen with coughing, sneezing, straining or laughing
- May have a headache at other times

Neck pain

- Constant headaches or they come and go
- May radiate to the shoulders or upper back

Dizziness or balance/coordination problems

- Feeling unsteady, especially when walking or turning quickly
- Poor fine motor skills

Muscle weakness or numbness

- Especially in the hands, arms or legs
- May cause clumsiness

Tingling or pins-and-needles sensations

- Common in the upper limbs and hands/feet

A hard time swallowing

- Feeling like food is "sticking"
- May be accompanied by gagging or choking

Sleep apnea, snoring or sleeping problems

- Interrupted breathing during sleep
- Often linked to brainstem compression in younger children who have central sleep apnea

Important notes

- The intensity of symptoms doesn't always match what we see on an MRI. Some people with a large tonsillar herniation feel fine, while others with a small one can have intense symptoms.
- Track your child's symptoms and share them with your doctor regularly.
- Always report new or worsening symptoms to your child's neurologist or neurosurgeon.
- It's normal for symptoms to develop later in life, so this may not be cause for concern. But you should always check with your child's doctor.
- It's also normal to have no symptoms at all.

How is CMI diagnosed?

It's diagnosed through imaging tests like:

- MRI (most common)
- CT (in some cases)

Your child's doctor may also check their reflexes, balance and neurological signs.

What are treatment options?

Treatment depends on your child's symptoms.

No symptoms or mild symptoms

- Regular monitoring (watchful waiting)
- Pain management (like headache treatment)

Moderate to severe symptoms

- Surgery may be an option.
- Posterior fossa decompression surgery creates more space for the brain and restores normal fluid flow.

How might CMI affect my child, generally?

- Many people live normal lives with little or no symptoms.
- Avoid activities that strain the neck or increase spinal pressure (heavy lifting, contact sports or straining).
- Tell any new healthcare providers about your child's condition before they have procedures like spinal taps.

When should I call my child's doctor?

Get medical help if your child has:

- Sudden or worsening headaches
- Weakness or numbness
- Loss of coordination
- A hard time breathing
- Trouble swallowing

Support and resources

- Conquer Chiari: conquerchiari.org
- Talk to a neurologist or neurosurgeon for specialized care.
- Join a local or virtual support group.

This family education sheet is available in Spanish.