

Idiopathic intracranial hypertension (IIH)



What is idiopathic intracranial hypertension?

Idiopathic intracranial hypertension (IIH) happens when the pressure inside the skull increases for no known reason.

- Idiopathic means the cause is not known.
- Intracranial means inside the skull.
- Hypertension means increased pressure.

IIH happens when:

- Too much cerebrospinal fluid (CSF) is made. CSF is the fluid around the brain and spinal cord. Extra CSF puts extra pressure on the brain.
- The CSF is not absorbed into the bloodstream as it should.

Sometimes doctors are not sure why IIH happens.

What causes IIH?

Most of the time the cause is not known. It may be linked to:

- Obesity (being very overweight).
- Taking too much vitamin A.
- Thyroid disease.
- Chronic kidney disease. Chronic means it lasts a long time and does not go away.
- Sleep apnea. Apnea means that breathing stops for a short time during sleep.
- Certain medicines.
- Abnormal clotting of the blood.

What are the possible symptoms?

Your child may have 1 or more of these:

- Headache
- Upset stomach or vomiting (throwing up)
- Ringing in the ears (tinnitus)
- Dizziness
- Blurry vision, double vision or blind spots
- Swelling of the nerve to the eye. This swelling can cause blindness if not treated.

What tests could my child have?

Your child may have 1 or more of these:

- Lumbar puncture (spinal tap) to check fluid pressure around the brain and spinal cord.

In case of an urgent concern or emergency, call 911 or go to the nearest emergency department right away.

Idiopathic intracranial hypertension, continued

- CT or MRI tests to take pictures of the inside of the brain or spine.
- Eye exam to check for swelling in the back of the eye.

What is the treatment?

Treatment guidelines may include:

- Repeat lumbar punctures to help drain CSF and decrease pressure inside the skull.
- Weight loss.
- Limiting the amount of salt that your child gets in food and drinks.
- Medicines, such as:
 - Acetazolamide (Diamox) to decrease fluid in the brain.
 - Diuretics to decrease the amount of fluid in the body by increasing the amount of urine your child has.
 - Migraine medicines to help ease headaches.
- Surgery to place a shunt. A shunt is a long, thin tube that drains extra CSF from the brain into the stomach area. A doctor called a neurosurgeon places the shunt during surgery.
- Stopping medicines that may be causing the problem.

When should I call the doctor?

Call the doctor if your child has:

- Headache.
- Upset stomach or vomiting (throwing up).
- Vision changes.

Also call if you have any questions or concerns about how your child looks or feels.

Does my child need follow-up care?

Your child may need to see:

- An eye doctor, also called an ophthalmologist.
- A neurosurgeon if your child needs or has surgery.
- A doctor who cares for people who have problems with their nervous system (neurologist).

This teaching sheet contains general information only. Talk with your child's doctor or a member of your child's healthcare team about specific care of your child.

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