

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) – the fluid around the brain and spinal cord – is made. This puts extra pressure on the brain.
- The CSF is not absorbed into the bloodstream as it should.

However, doctors are not always sure why IIH happens.

CSF normally surrounds the brain and spinal cord. The CSF helps to protect and cushion them.

- When there is too much CSF inside the hard, bony skull, the pressure increases above normal.
- The increased pressure can cause problems, such as:
 - Headache
 - Upset stomach or vomiting (throwing up)
 - Ringing in the ears (tinnitus)
 - Double vision and blind spots
 - Swelling of the nerve to the eye. This swelling can cause blindness if not treated.

What causes IIH?

Most of the time the cause is unknown but may be linked to these things:

- 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 throughout sleep.
- Certain medicines
- Abnormal clotting of the blood

What are the possible symptoms?

Your child may have one or more of these:

- Headache
- Upset stomach or vomiting (throwing up)

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

Idiopathic intracranial hypertension, continued

- Ringing in the ears (tinnitus)
- Vision changes, such as blurry vision, double vision, enlarged blind spot or blindness
- Being dizzy

What medical tests could my child have?

Your child may have one or more of these:

- Lumbar puncture (spinal tap) – to check fluid pressure around the brain and spinal cord
- 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 salt intake in food and liquids
- Medicines, such as:
 - Acetazolamide (Diamox) – to decrease fluid in the brain
 - Diuretics – to decrease the amount of fluid in the body by increasing urine output
 - Migraine medicines – to help ease headaches
- Surgery to place a shunt. A shunt is a long, thin tube that drains excess CSF from the brain into the stomach area. A doctor (neurosurgeon) places the shunt during surgery.
- Stopping medicines that may be causing the problem

When should I call the doctor?

Call your child's doctor if your child has any of these:

- 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.

Is follow-up care needed?

Your child may need to follow up with:

- An eye doctor (ophthalmologist)
- A neurosurgeon if your child 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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