

Diagnosis:

Idiopathic Intracranial Hypertension

What is it?

Idiopathic intracranial hypertension (IIH) occurs when there is an increase of pressure inside the skull with no known cause.

- Idiopathic means the cause is unknown
- Intracranial means inside the skull
- Hypertension means high pressure

It is caused by an excess of the fluid that sits around the brain and spinal cord, known as cerebrospinal fluid (CSF), which builds up in the skull and creates pressure on the brain and optic nerve.

Note that there are also forms of intracranial hypertension that *do* have a known cause, and are therefore not idiopathic, that may include different treatment protocols.

Health Impacts

If left untreated, IIH can result in permanent issues including vision loss. Symptoms can also recur, even after treatment, so monitoring and check-ups are important.

Symptoms

Symptoms include, but are not limited to:

- Headaches, often accompanied by nausea and vomiting
- Eyesight changes (blurry vision, double vision, blind spots, temporary blindness, loss of peripheral vision)
- Persistent ear ringing (tinnitus)
- Dizziness
- Nausea
- Vomiting
- Neck stiffness and pain
- Shoulder pain
- Difficulty Walking
- Depression

Weight Stigma in Diagnosis & Treatment

While IIH happens to people of all sizes, when it happens in higher-weight people there is a tendency for healthcare practitioners to assume weight is to blame and to prescribe weight loss, despite the [extremely high failure rate](#) and other dangers of intentional weight loss attempts. Some healthcare practitioners have been known to insist that IIH it is caused by “ob*sity” despite the fact that the first I stands for Idiopathic which means that the cause is unknown, and the fact that most higher weight people do not have IIH and some lower weight people do.

Diagnosis

An optometrist may perform a dilated eye exam and a visual field test to check peripheral vision.

A neurologist may perform tests including a physical exam, head CT or MRI, and/or a lumbar puncture (spinal tap) to test the pressure of the CSF.

The diagnostic criteria for a lumbar puncture requires CSF opening pressure greater than 250 mmCSF. A repeat LP may be performed if opening pressure is below 250 mmCSF but there is a strong suspicion of IIH.

Treatment Options

Treatment may vary based on the severity of symptoms.

Note: While weight loss is a frequently recommended treatment, we cannot ethically recommend it for the [reasons stated here](#). We also point out that the amount of weight loss is usually a recommended percentage for example 10% of body weight. This means that a person who is 300 pounds at diagnosis would be told that they should get to 270 pounds as a “treatment” but a person who weighs 270 pounds at diagnosis would be told that they need to get to 243 pounds, meanwhile a person who weighs 200 pounds at diagnosis would be told they need to get to 180 pounds. We challenge both the scientific rigor and basic logic of this advice.

Treatments may include:

- Limiting fluids or salt in the diet
- Medications (be sure to ask your healthcare provider for a thorough informed consent discussion regarding side effects)
- Diuretic medication to help the body release excess fluid
- Acetazolamide (Diamox) or Topiramate to help your body make less CSF
- A spinal tap to reduce pressure by removing fluid
- Optic nerve surgery to ease pressure and preserve vision
- A surgically placed shunt (tube) in the brain to drain fluid

Notes:

- A Cochrane review found that “There remains insufficient evidence on the efficacy of acetazolamide or any other treatments currently available for treating people with IIH.”
- A recent study on GLP1s (like Ozempic/Wegovy and Zepbound) found no reduction in MHD or Papilledema (swelling of the optic disc due to elevated intracranial pressure,) and no changes in visual impairment.