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MADISON NEUROLOGY LLC

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Neurology Care 7 days a Week. Because Your Brain Matters.

Idiopathic Intracranial Hypertension (Pseudotumor Cerebri)

Patient education guide · Headache & Facial Pain · Madison Neurology LLC

What is it?

Idiopathic intracranial hypertension (IIH) is a condition of abnormally high pressure in the fluid around the brain and spinal cord, without a tumor or other structural cause — hence the older name 'pseudotumor cerebri.' It mainly affects women of childbearing age with obesity. Its two great threats are chronic headache and, most importantly, permanent vision loss if untreated.

How does it happen?

The exact mechanism is unknown, but weight gain is the dominant driver — even modest recent gain can trigger it, and modest loss can reverse it. Certain medications (tetracycline antibiotics, excess vitamin A, some hormonal treatments) can also cause it. Sleep apnea is a common fellow traveler.

Common symptoms

- Daily headache, often worse in the morning or lying down
- Pulsatile tinnitus — a rhythmic whooshing in the ears in time with the heartbeat
- Transient visual obscurations — brief (seconds) dimming or blackouts of vision, often on standing
- Blind spots, peripheral vision loss, or double vision
- Neck and shoulder pain

How is it diagnosed?

MRI (or CT) excludes other causes of raised pressure and often shows telltale signs (empty sella, flattened globes, dilated optic nerve sheaths). A lumbar puncture confirms elevated opening pressure and rules out other problems — and often temporarily relieves the headache. Formal visual field testing tracks the vision threat. Ophthalmology and neurology co-manage the condition.

How is it treated?

Weight loss is the disease-modifying treatment: sustained loss of 10-15% of body weight can put IIH into remission (structured programs and, in selected cases, bariatric surgery have the best evidence). Acetazolamide reduces pressure and is standard therapy; topiramate helps both pressure and headache. Urgent surgical options (optic nerve sheath fenestration, CSF shunting, or venous sinus stenting in appropriate anatomy) protect vision when it is threatened. Serial visual field checks guide everything.

What does the future hold?

With treatment, most patients' vision is protected and many achieve remission with weight loss. Headache often needs separate, migraine-style management. Weight regain commonly reactivates the disease, so long-term weight strategy is central. Pregnancy requires planning but is usually manageable.

Questions patients commonly ask

Q: Can I lose my sight?

A: That is the condition's real danger — which is why visual fields are monitored regularly and treatment is escalated promptly if vision worsens. With proper care, most people keep good vision.

Q: How much weight do I need to lose?

A: Studies show 10-15% body weight loss can induce remission; even smaller losses reduce pressure.

Q: Why do I hear a whooshing sound?

A: High fluid pressure transmits the pulse into the veins of the skull — the whooshing typically settles as pressure is controlled.

National support groups & resources

- **Intracranial Hypertension Research Foundation** — ihrfoundation.org
- **National Organization for Rare Disorders** — rarediseases.org — 1-800-999-6673
- **American Academy of Neurology — Brain & Life patient resources** — brainandlife.org

(Organization contact details were current at the time of compilation; please verify online.)

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