CONDITION

Idiopathic intracranial hypertension

Idiopathic intracranial hypertension is raised pressure around the brain without an identifiable cause.

WHAT IT IS
Raised pressure around the brain without an identified cause

BODY SYSTEM
Nervous system and eyes

MAIN SYMPTOMS
Headache, brief visual dimming, pulsing ear noise, double vision

WHAT CAUSES IT
Unknown, often linked with obesity and recent weight gain

HOW IT IS DIAGNOSED
Eye examination, brain imaging, and lumbar puncture

MAIN TREATMENT
Weight management, pressure-lowering medicines, sometimes surgery

CAN IT BE CURED?
Sometimes - pressure and optic nerve swelling resolve

IS IT AN EMERGENCY?
Sometimes - sudden or rapidly worsening vision loss

LONG-TERM OUTLOOK
Vision often preserved with treatment; headaches may persist

Overview

Idiopathic intracranial hypertension, or IIH, is a condition in which pressure rises inside the skull without an identifiable cause. "Idiopathic" means that no specific cause has been found.

The brain and spinal cord are surrounded by cerebrospinal fluid, a clear liquid that cushions and protects them. In IIH, the pressure of this fluid is too high. Brain scans do not show a tumour, a blockage causing excess fluid, or another clear explanation for the pressure.

Raised pressure can cause headaches and swelling of the optic nerves, which connect the eyes to the brain. This swelling is called papilloedema. If it is not controlled, it can damage sight. IIH is not a brain tumour, and it does not turn into one.

IIH is often associated with obesity or recent weight gain, especially in women of childbearing

age. However, people of any sex, age, or body size can develop it. Weight should not be assumed to be the explanation until other causes of raised pressure have been excluded.

Symptoms

Headache is the most common symptom. It may be present daily or resemble migraine, with throbbing pain, nausea, or sensitivity to light and sound. It may feel worse when coughing, straining, bending, or lying down, but these features are not present in everyone.

Symptoms affecting vision can include:

Brief dimming may last only seconds, often after standing, bending, or straining. Any new or worsening change in sight needs prompt assessment because people may not notice gradual loss of side vision.

Some people hear a pulsing or whooshing sound in one or both ears. This is called pulsatile tinnitus because it often keeps time with the heartbeat.

Other possible symptoms include neck or shoulder pain, dizziness, nausea, and problems with balance. Thinking and concentration may feel more difficult, especially when pain or poor sleep is present.

Symptoms alone cannot confirm IIH. Migraine and several other conditions can cause similar headaches or visual symptoms.

- Brief episodes in which vision dims or goes grey
- Blurred vision or loss of part of the visual field
- Double vision
- Flashes of light
- Reduced side vision

Causes and risk factors

The exact cause of IIH is unknown. It may involve problems with how cerebrospinal fluid and blood drain from the head, but there is no single proven explanation.

Strongly recognised associations include obesity and recent weight gain. These are risk factors rather than proof that body weight caused an individual case. IIH can also occur in people who are not overweight.

Some medicines and medical conditions can cause raised pressure that resembles IIH.

Examples include vitamin A derivatives used for acne, tetracycline antibiotics, growth hormone treatment, and withdrawal from long-term corticosteroids like prednisone or hydrocortisone . Anaemia, sleep apnoea, kidney problems, and certain hormone conditions may also be relevant.

When a medicine or another condition explains the pressure, it is considered secondary intracranial hypertension rather than idiopathic intracranial hypertension. Do not stop a prescribed medicine without medical advice, because sudden withdrawal may itself be harmful.

IIH is not generally considered an inherited condition. Having a relative with it does not mean that you will develop it.

Diagnosis

Diagnosis usually begins with an eye and neurological examination. An eye specialist may look for papilloedema and check visual sharpness, colour vision, eye movements, and the pupils.

A visual field test measures central and side vision. Photographs or optical coherence tomography, known as OCT, may be used to measure the optic nerve and track swelling over time. OCT is a quick, non-invasive scan of the back of the eye.

Brain imaging is needed to rule out other causes of raised pressure. Magnetic resonance imaging, or MRI, is commonly used. Imaging of the veins in the head, called MR venography or CT venography, helps exclude a blood clot in the brain's venous channels.

A lumbar puncture is usually required after imaging. During this procedure, a needle is placed in the lower back to measure the pressure of the cerebrospinal fluid and collect a sample. The fluid should have a normal composition in IIH. The opening-pressure result must be interpreted alongside symptoms, eye findings, scan results, body position, and the circumstances of the procedure.

Some scans show changes associated with raised pressure, such as flattening at the back of the eye or narrowing of large veins. These findings can support the diagnosis, but they do not confirm IIH by themselves.

Rarely, raised pressure is diagnosed without visible papilloedema. This requires careful specialist assessment because chronic migraine is much more common and can have similar symptoms.

Treatment and management

Treatment has two main aims: protecting sight and reducing the effect of headaches and other symptoms. The urgency of treatment is guided mainly by optic nerve swelling and visual field results.

For people whose IIH is associated with excess weight, supported weight management is an important part of care. Weight loss can reduce pressure and may bring the condition into remission. This can be difficult while living with headaches, fatigue, or weight-promoting medicines. Support may include dietary care, a structured weight programme, or, for selected people, bariatric surgery. Care should be respectful and should not reduce the condition to body weight alone.

Acetazolamide is commonly used to reduce the production of cerebrospinal fluid. Possible effects include tingling in the fingers or toes, altered taste, tiredness, stomach symptoms, and changes in body salts. Kidney stones can occur. Monitoring and the choice of medicine depend on individual health needs.

Topiramate is sometimes considered because it can help prevent migraine and may reduce appetite as well as pressure. It also has possible adverse effects and important pregnancy-related risks. Anyone who is pregnant, planning pregnancy, or able to become pregnant should have their medicines reviewed rather than stopping them without guidance.

Headaches may need separate treatment based on whether they resemble migraine or another headache type. Frequent use of painkillers can lead to medication-overuse headache, which makes headaches more persistent. A headache diary can help show patterns and treatment response.

A lumbar puncture may briefly lower pressure, but fluid is replaced quickly. Repeated lumbar punctures are therefore not usually used as long-term treatment.

If sight is worsening quickly despite treatment, surgery may be needed. Options include:

Each procedure has risks and may require further treatment later. Venous stenting is not suitable for everyone, and its long-term role continues to be studied.

- A cerebrospinal fluid shunt to drain fluid elsewhere in the body
- Optic nerve sheath fenestration to release pressure around an optic nerve
- Venous sinus stenting for carefully selected people with narrowed head veins

Complications

The most important complication is permanent loss of vision from ongoing optic nerve damage. Loss may begin at the edges of the visual field and can be difficult to notice without

testing. Severe, rapid visual decline can occur, although it is not the usual course.

Headaches can continue even after pressure and papilloedema improve. This does not always mean that the pressure has risen again. Migraine, medication overuse, sleep problems, and other headache triggers may still need attention.

Shunts can become blocked, infected, or drain too much fluid. Other procedures also carry risks, so ongoing review may be needed after surgery.

Persistent pain, pulsing noise, visual uncertainty, and repeated appointments can affect sleep, work, study, driving, and mental health. Support for these effects is part of managing the condition.

Prevention

IIH cannot always be prevented because its underlying cause is unknown.

For people with weight-associated IIH, avoiding substantial weight regain may reduce the chance of recurrence after remission. This is not a guarantee, and weight change should be approached with appropriate support rather than blame.

Medicines known to be associated with raised pressure should be reviewed if symptoms develop. They should not be stopped or avoided automatically, because the benefits and risks differ from person to person.

There is no proven supplement, exercise, or special diet that prevents IIH in everyone.

Living with it and what to expect

The course of IIH differs between people. With treatment and regular eye monitoring, many retain useful vision and eventually have resolution of papilloedema. Some enter remission, while others need treatment over a longer period or experience a recurrence.

Headaches often improve more slowly than optic nerve swelling. They may continue for months or years even when eye examinations suggest that pressure is controlled. Ongoing headache care can therefore remain important after the immediate risk to sight has fallen.

Follow-up usually includes visual field testing and examination or imaging of the optic nerves. Visits may be frequent when swelling is severe or vision is changing. Stable or resolved IIH usually needs less frequent review, based on specialist advice.

Report new weight gain, returning pulsing sounds, brief visual dimming, or other recurring symptoms during follow-up. These do not prove that IIH has returned, but they may justify

another assessment.

Pregnancy is possible for many people with IIH. Planning ahead allows medicines, weight care, and eye monitoring to be reviewed. Pregnancy does not automatically require a particular type of birth, but active or sight-threatening IIH needs coordinated obstetric, neurology, and eye care.

Driving may be affected if visual fields or visual sharpness do not meet local legal standards. An eye specialist can explain how test results relate to driving rules.

When to get medical help

Arrange a prompt medical or eye-care appointment if you develop new persistent headaches, pulsing noise in the ears, repeated episodes of dim vision, double vision, or unexplained visual changes. These symptoms have several possible causes and need assessment rather than self-diagnosis.

If you have diagnosed IIH, contact your usual care team promptly if symptoms return or become more frequent. Routine follow-up remains important even when you feel well because side-vision changes may not be obvious.

Seek same-day urgent assessment for:

Call emergency services for a sudden "worst-ever" headache, collapse, confusion, seizure, weakness on one side, difficulty speaking, or loss of consciousness. These are not typical symptoms to monitor at home and may indicate another urgent condition.

- New loss of vision or rapidly worsening vision
- A dark area, marked blurring, or major loss of side vision
- New persistent double vision with a severe headache
- Repeated vomiting with worsening headache or visual symptoms

Common questions

Is idiopathic intracranial hypertension a brain tumour?

No. IIH causes raised pressure without a tumour or another mass in the brain. Brain imaging is performed to rule out a tumour and other possible causes.

Can IIH go away completely?

Sometimes. Pressure and papilloedema can resolve, and some people enter long-term

remission. Recurrence is possible, particularly after substantial weight gain, so new symptoms should still be assessed.

Will a lumbar puncture cure IIH?

Usually not. Removing fluid can lower pressure and ease symptoms for a short time, but the body quickly replaces the fluid. The procedure is mainly used to measure pressure and analyse the fluid.

Does losing weight cure IIH?

Weight loss can lower pressure and lead to remission in people with weight-associated IIH, but it is not an instant or guaranteed cure. People who are not overweight may also develop the condition and need other management.

Why do I still have headaches if my eye swelling is better?

Headache can continue after pressure and papilloedema improve. The headache may behave like migraine or be affected by medication overuse, sleep, or other factors. Persistent headache does not by itself prove that pressure remains high.

Can I exercise with IIH?

Many people can exercise, and gradual activity may support general health and weight management. The suitable type and pace depend on symptoms, vision, and any recent procedure. Stop and seek advice if activity causes major visual change, fainting, or a sudden severe headache.

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