

Notes

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Version 2. Published December 2022. Due for review December 2025. 1638

Patient information factsheet

Idiopathic intracranial hypertension

What is idiopathic intracranial hypertension (IIH)?

IIH is a condition where the fluid surrounding the brain is at a higher pressure than normal. This fluid, which is similar to water, is called cerebrospinal fluid (CSF). As well as surrounding the brain, CSF also surrounds the spinal cord as well as some nerves, including the optic nerves that carry information about vision from our eyes to our brain.

How common is IIH?

- This condition affects 1 to 2 people in every 100,000, which means it is not very common.
- It is more common in women and people who are overweight.

Causes

'Idiopathic' is a medical term which means that the cause is not known. However, we do know that there are important factors that increase the risk of getting the condition:

- The most common risk factor is gaining weight or being overweight.
- Certain medications increase a person's chance of suffering from IIH. These include tetracycline antibiotics, steroids, high doses of vitamin A and growth hormone.

Symptoms

- Headache is the most common symptom. Some people get headaches even after the high pressure in the CSF is treated.
- Some people experience temporary loss of vision in one or both eyes which can last seconds, especially when straining or bending over. These are called 'visual obscurations'.
- There may be other disturbances of vision such as blurred vision, dimming of vision, losing parts of the vision, double vision, seeing flashing lights or problems with seeing colours.
- A 'whooshing' noise in the ears may occur.
- Some people with IIH have no symptoms at all and the condition is picked up at a routine eye test.

Tests to diagnose IIH

- **Eye examination:** this test involves a special tool called an ophthalmoscope to look for swelling at the back of your eyes around your optic nerves (this type of swelling is called 'papilloedema').
- **Visual acuity:** this test involves reading letters on a wall chart to check the clarity of your vision.
- **Visual field test:** this test assesses how well you can see objects throughout your field of vision.
- **MRI or CT scan of your brain:** this test looks at your brain to make sure that there is no other cause for the raised pressure.
- **Lumbar puncture:** this is perhaps the most important test as it can confirm whether you have high pressure in your CSF and can exclude other causes of raised pressure. It is a minor outpatient procedure and takes around 30 minutes. A qualified healthcare professional will inject a local anaesthetic (numbing injection) into your lower back and then insert a thin needle between the bones in your lower back to measure the pressure of the fluid in your spinal cord. They will also take some CSF samples. This test may temporarily relieve the pressure, but it is not a long-term treatment.

Treatment

Weight loss

- Weight loss is the most important treatment for IIH. Many medical research studies have shown that losing weight is very effective at reducing the fluid pressure, headaches and problems with vision.
- Research suggests that a 6% decrease in body weight can help to resolve swelling at the back of the eye and usually a weight loss of 5 to 10% will significantly improve the condition.
- Your doctor may refer you to a weight loss programme. If this is unsuccessful, weight loss surgery may be considered for people who are very overweight with a body mass index (BMI) of over 35.

Medication

- Your doctor may prescribe a medication that will help lower the fluid production in your body. Medications must be used alongside weight loss.
- The most commonly prescribed medication is a water tablet called acetazolamide (Diamox). It is important to note that many people will experience side effects such as tingling of the fingers and toes and around the mouth, and occasional stomach pain or a funny taste in the mouth.
- Other medications include topiramate, furosemide and bendroflumethiazide.

Painkillers

- We suggest avoiding painkillers if possible. Those containing codeine, dihydrocodeine, morphine, tramadol and caffeine should be avoided in particular since they may make your headaches worse if taken frequently (more than ten days per month). This is called 'analgesic associated headache'.

Surgery

- Surgery is only considered when weight loss and medications have failed and there are significant visual problems arising from the condition.
- There are a few surgical options available, but these all carry risks and potential complications and should not be seen as a 'magic cure'.
- **Neurosurgical CSF 'shunting' (the most commonly used procedure):** This is where a plastic tube is placed permanently inside the body with one end draining the fluid, and the other end depositing it into the abdomen (tummy). There are two types of shunt commonly used:
 - **Lumbo-peritoneal shunt:** one end of the tube is placed into the lower back to drain CSF from there into the abdomen.
 - **Ventricular peritoneal shunt:** one end of the tube is placed directly into one of the fluid compartments of the brain (called ventricles) to drain CSF from there into the abdomen.
- **Venous sinus stenting:** This is where a small tube (stent) is placed inside a blood vessel (vein) in the brain. This helps reduce the CSF pressure by improving drainage of fluid from the brain via these veins. A special x-ray of the blood vessels (called an angiogram) will be done first to see if there is evidence of narrowing in any veins. This procedure is only suitable for a small proportion of people with a specific type of IIH (called venogenic IIH).
- **Bariatric (weight loss) surgery:** Surgery to the stomach (such as a gastric band) to reduce weight may be offered to people with IIH who are very overweight (with a body mass index or BMI over 35).

Can I go on holiday or travel by air?

- It is safe to fly with this condition as long as you feel well in yourself.
- When travelling, it is important that you have valid travel insurance. You should inform your insurance company that you have IIH and ensure you read the small print to see what the insurance will cover.
- Make sure you take your medications with you so you don't run out while on holiday.

Contraception

- There is some suggestion that the combined oral contraceptive pill may increase the risk of IIH but this has not been confirmed.
- Many women with IIH are taking the pill but this may just be a coincidence. We suggest that if you feel that the pill has increased your symptoms, you should use an alternative form of contraception that does not contain oestrogen (discuss the options with your GP).

Pregnancy

- It is advisable to speak to your neurologist before planning a pregnancy.
- If your IIH is not well-controlled, your doctor may recommend that you wait until your health is more settled before trying for a baby.
- There is no evidence that pregnancy itself causes IIH or makes it worse. However, gaining excessive weight during pregnancy will often make the condition worse.
- The medications used to treat IIH may pose a risk to an unborn baby. Therefore, you must inform your doctor if you are pregnant or are thinking of getting pregnant as your medication may need to be changed.
- There is no need to have a caesarean section if you have IIH unless it is needed for another reason. A normal vaginal delivery is safe.
- It is safe to have a lumbar puncture if it is needed during pregnancy.

Long-term outlook for IIH

- The main risk of IIH, if it remains untreated, is permanent damage to your vision. Fortunately this is rare, but if you are concerned that your vision has deteriorated, you should seek medical attention urgently.
- Some people's symptoms improve quickly with weight loss alone. If medications are needed, most people are able to do without these after a few years.
- Some people with IIH continue to be prone to headaches even after the high CSF pressure is effectively treated and remains normal. These headaches are often similar to migraines and are treated in a similar way.

Further information and support

www.nhs.uk/conditions/intracranial-hypertension

www.iih.org.uk

Facebook – IIH support group

Help with following a healthy diet and lifestyle

www.nhs.uk/live-well

www.myfitnesspal.com