

## What is Idiopathic Intracranial Hypertension?

Idiopathic intracranial hypertension (IIH), also known as Benign Intracranial Hypertension or pseudotumour cerebri, is a condition with an unknown cause or causes. The condition is associated with raised fluid pressure around the brain (raised intracranial pressure). The fluid that cushions the brain is called cerebrospinal fluid (CSF).

It can cause disabling daily headaches and visual loss, which can be permanent. The raised fluid pressure can compress the nerves supplying the eye (also known as papilloedema) and this can affect vision.

This booklet will describe the potential effects IIH can have on the eyes.

### **How does IIH cause problems with vision?**

The fluid that cushions the brain (or CSF) also surrounds the optic nerves as they pass through the skull into the eye sockets. When the CSF pressure (intracranial pressure) is high, this flows to increased pressure around the optic nerves. The resulting swelling of the optic nerves can be seen on your eye examination and is called papilloedema.

The optic nerves pass information from the eye to the brain. Papilloedema causes problems in the optic nerves resulting in temporary loss of vision (visual obscurations) and constriction of the peripheral field of vision.

Raised intracranial pressure can also put pressure on or stretch of some of the nerves that control eye movement, causing double vision.

## **What eye symptoms can happen in IIH?**

Some people with IIH may not have any eye problems at all, even if they have papilloedema. For this reason, it is important that eye tests are done, as there could be a problem with the vision if not picked up.

On the whole most people with IIH will notice a problem at times with their vision. These can include:

- Transient visual obscurations (short lived loss of vision)
- Double vision
- Visual blurring
- Loss of vision.

## **What are transient visual obscurations?**

This term describes short disturbances in the vision that typically last for a few seconds, after which the vision returns to normal. These disturbances can present in different ways. Some describe “black-outs” in a part, or all, of the field of vision. Sometimes these are described as a “greying-out” or a “white-out” as well. Others will report these episodes as blurriness or difficulty focusing.

The transient visual obscurations happen more with changes in body position (such as bending over or getting up from a bed or chair) and with “Valsalva” type maneuvers. These are maneuvers that cause a temporary increase in pressure to the head (such as straining in constipation, coughing, or lifting heavy objects).

## **What is double vision?**

Double vision happens when the brain sees two images of one real object. With “binocular” (both eye) double vision, this results from the two eyes being misaligned (pointing in different directions).

In IIH the increased fluid pressure around the brain can put pressure on, or stretch the nerves that control eye movement, causing an unbalance and misalignment of the eyes.

## **What problems can there be with the field of vision?**

There are three main types of visual field problem that can happen in IIH. These are:

- An enlarged “blind spot”
- Peripheral visual field constriction
- Central loss of vision
- An enlarged “blind spot”

Every human has a blind spot in their field of vision due to where the eye nerve joins the back of the eye from the brain. We are not generally aware of it, although we can find it by closing one eye and carefully moving a small object within our visual field. In IIH with papilloedema where there is enlargement of the optic nerve head with the swelling, the blind spot therefore increases in size. This can be plotted on the field of vision test.

- Visual field constriction

This happens when the peripheral (outside) vision of an eye is reduced. Peripheral vision helps a person to orient themselves and navigate by being aware of objects in their surrounding environment. Visual field

constriction (loss of sensitivity of the peripheral field) can cause a person to trip over, or bump into objects that they are not aware of. Often people are not aware this is happening, until there is a severe loss of vision. Then they may sometimes report being startled by objects suddenly appearing in their field of vision as well.

- Central loss of vision

This is a very serious sign in IIH. When someone notices their central vision become permanently blurry it could mean that the fluid from the eye nerve is now tracking underneath the retina.

## **How does the vision change with treatment?**

For some people with IIH once, vision is starting to be lost, unless rapidly treated it could be permanent. Fortunately, for most people, there is a reasonable window of time to prevent, or reverse some of these changes with timely treatment.

It is worth knowing that sometimes vision can also be affected by the medical treatments of IIH. Both acetazolamide and topiramate can cause excessive tiredness/fatigue and decreased cognitive functioning (brain fog) that affects the eyes ability to focus clearly. Topiramate can also rarely cause an emergency elevation in eye pressure (intraocular pressure), this is called acute angle closure glaucoma. For more information, see the IIHUK topiramate drug information booklet.

Some surgical treatments for IIH, like optic nerve sheath fenestration, can have been reported to have rare complications that occur causing permanent sight loss. For more information, see the IIHUK Optic nerve sheath fenestration leaflet.

It is important to note that severe vision loss from IIH is not common, and with regular eye assessment to monitor for early changes, together we can prevent this from happening by putting the IIH into remission.

## **What is IIH ocular remission?**

The aim of IIH treatment is to achieve remission. The cause of IIH is still unknown, and therefore there is currently no cure for the condition. There are times when the eye symptoms and the papilloedema of the optic nerves resolve, but the headaches remain. This situation is termed “ocular” remission. These “left-over” headaches often mimic migraine and respond well to migraine treatments.

## **Summary of eye problems in IIH**

Visual problems caused by IIH, if caught early enough, are often reversible. If you notice an increase in your eye symptoms you should contact your doctor.

However, relapses in IIH and delays in recognising progression through regular assessment by an ophthalmologist can result in permanent vision loss.

## Where can I get more information?

IIH UK

website

[www.IIH.org.uk](http://www.IIH.org.uk)

IIH Consensus

Guidelines[http://](http://jnnp.bmj.com)

[jnnp.bmj.com](http://jnnp.bmj.com)

A team of people contributed to this booklet. It was written by A. Fong. Critically reviewed by S. Mollan. It was assessed in the draft stage by the ophthalmology nursing team at University Hospitals Birmingham (UHB). It was reviewed by a group of patients who have IIH, and also assessed by friends and family that attended the Joint Idiopathic Intracranial Hypertension clinic at UHB. It was critically reviewed by the IIHUK trustees. S Mollan is responsible for the final version. The views expressed in this booklet are of the authors and not their employers or other organisations.

Please note we have made every effort to ensure the content of this is correct at time of publication, but remember that information about the condition and drugs may change.

This information booklet is for general education only.

For full details see the information leaflet that comes with the medicine.

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