

Working to relieve the pressure!

Some of the most worrying symptoms of IIH are the visual problems that can affect many sufferers. This leaflet is designed to tell you of some of the visual problems reported by sufferers or which may be referred to by the medical profession. It is important to be aware that not all sufferers of IIH will have all of these symptoms and some people experience no visual problems at all.

In addition to the symptoms covered in this leaflet, 44% of IIH patients report pain behind the eye, and 22% report pain with eye movement.

Blurred vision and loss of visual acuity

Perhaps one of the most common symptoms of IIH is the blurred vision and loss of visual acuity which the majority of IIH sufferers have, and it's often this which makes people first visit their doctor or optician, where the symptoms of IIH are noticed. Up to 68% of IIH patients have transient visual obscurations or blurring (International Perimetric Society, 2002). This blurring or loss of visual acuity can be due to pressure on the cranial nerves, which control the movements of the eyes, including the contraction and dilation of the pupil which regulates both how much light enters the eye and focusing on things. Sometimes, the medication which is used to treat IIH can cause blurring of the vision or temporary short-sightedness. Diamox (Acetazolamide) can cause blurred vision, although this is most common where Diamox is used in high dosage. This usually subsides if the dosage is reduced, or treatment is stopped.

Changes in colour vision or after-images

Some sufferers of IIH have reported changes in their colour vision. For example colours may seem 'faded' or have a slightly different tone. Spells of vision with 'colour casts' where everything seems to be tinged with the same colour have also been reported. Others have reported having difficulties with 'after-images' being able to see an object after you have stopped looking directly at it. The after-image may or may not be an inverted colour. Because of the nature of IIH, not everyone has this, and it is rare, so not all neurologists will accept that IIH is the cause of these symptoms.



Diplopia

Diplopia is commonly known as double vision and normally occurs with binocular vision (using both eyes), but very occasionally it can still happen when one eye is closed. Some sufferers have permanent double vision, caused by high CSF pressure damaging the nerves that move the eyes, but it is also common to have temporary episodes. The symptom can sometimes improve with diuretic treatment.

Enlarged Blind Spot

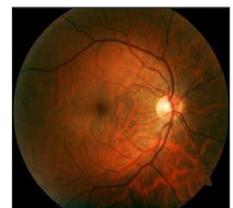
Everyone has a blind spot in their vision – it's caused by a gap in the retina where the optic nerve is attached to the back of the eye. It is not normally noticed as the brain compensates for the missing vision by 'filling in the gaps'. Sometimes, sufferers of IIH have an increased or enlarged blind spot.

This may become big enough to notice gaps in vision, but is often only picked up during visual field tests. As with other symptoms, this may become permanent, but can improve after drug treatment or surgical intervention.

Papilloedema

Papilloedema is the name given to swelling of the optic nerve at the back of the eye. This is sometimes the first sign of IIH, picked up during a routine eye check, although it's possible to have the condition without papilloedema, however, many sufferers of IIH have this symptom. The photograph shows a healthy human retina, with a well-defined optic disc (the bright circular area towards the right of the image), and a normal blind spot.

In IIH with papilloedema, the head of the optic nerve bulges into the back of the eye, and there is blurring of the edges of the optic disc.



Photophobia

Many IIH sufferers have this symptom. Photophobia literally means 'fear of light', but is somewhat misnamed. With photophobia bright light is actually painful to the eyes, and also increases the headache pain. Some people feel 'blinded' by strong light or even normal daylight and need to be in a dark environment. In rare

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cases, the nerves signalling to the muscles moving the iris can become damaged, and the iris will not react as quickly as normal to light, intensifying the difficulty.

Reduced or Fluctuating Visual Fields

The visual field is the amount of space extending in all directions that can be seen by the eye without changing its position. It's normal for a person diagnosed with IIH to have a visual field test. The test consists of you looking into a special machine, focussing on a single spot, and pressing a button each time you see a light. The lights appear randomly at different places in the visual field, and your responses build a map of how much peripheral vision you have, and the size of your blind spot.

If untreated, pressure on the optic nerve can lead to visual field loss. This is likely to be initially in one quadrant of vision, for example it is possible to lose vision just in the top right, so you can't see anything above and to the right of you. Eventually this could become permanent, although it is common to have temporary losses, which improve with treatment or when pressure reduces. If completely untreated, it is possible to lose vision in all four quadrants, leading to tunnel vision or even blindness in one or both eyes.

Transient Visual Obscurations

This term is given to periods of 'greying out' of vision, experienced by many people with IIH. This can be quite alarming, as sight literally fades away and everything becomes grey and foggy. It can affect only one eye or both eyes together. These episodes usually only last for a few seconds and often, though not always, are accompanied by severe headache.

Normal treatment for IIH can reduce their incidence, or stop them completely. There is no evidence to suggest that these incidents are a danger to long term vision.

Depth perception and spatial awareness

Possibly one of the most limiting of the visual symptoms, and the cause of the most loss of independence, is problems with depth perception and spatial awareness. Stairs, curbs, and crossing roads can all become a nightmare for an IIH sufferer, unsure of how deep a drop is and how fast traffic is moving. The problems with depth perception and spatial awareness can make crowded places seem very daunting, especially if someone with IIH has peripheral vision loss, as people can appear from 'nowhere' and crowds can be very confusing.

With treatment many of the visual problems associated with IIH can be controlled, and the occurrence of visual problems with IIH doesn't signify permanent vision damage. Approximately 5% of IIH sufferers lose some or all of their vision in at least one eye. These are usually patients who do not return for follow-up evaluation or seek attention too late after visual symptoms have presented. Vision loss may not be permanent and can improve with treatment suggested by your doctors. If you are prescribed medication such as Acetazolamide to help reduce ICP, stopping this medication may result in vision loss due to increase of CSF. Always consult your Doctor before stopping medication.

