

## Working to relieve the pressure!

A diagnosis of Idiopathic Intracranial Hypertension (IIH) can be a shock to both the person diagnosed and those who care for them. IIH is a relatively rare disorder and it can be difficult to find detailed information on the condition. IIH is also known as Pseudotumor Cerebri (PTC) and Benign Intracranial Hypertension (BIH). Symptoms of IIH can include severe headache, papilloedema (swelling of the optic nerves), temporary loss of vision (transient visual obscuration) blurred vision, double vision and decreased visual acuity (sharpness of vision), pulsatile tinnitus (hearing your pulse as a 'whooshing' sound in your ears and head), and pain with eye movement.

Other symptoms reported by sufferers include but are not limited to: nausea, vomiting, fatigue, photophobia (dislike of and pain caused by bright light), problems with balance and spatial awareness, aphasia (difficulty using or understanding words), disorientation, loss of short-term memory (sometimes also long-term memory loss), confusion, feeling 'spaced out', decreased depth perception and peripheral vision. Some children are often too young to report their symptoms adequately and can present with many non-specific symptoms. Although many sufferers have symptoms in common, each sufferer is an individual and should be treated accordingly.

### Coping with the symptoms

IIH is an invisible condition and for those watching on it is hard to understand what the sufferer feels or is experiencing. For the person with IIH the symptoms can be extremely debilitating and disabling. That said, IIH affects everyone differently, some sufferers may have more severe symptoms than others. Sufferers may no longer be able to enjoy social activities and may be limited in the type of activities they can do. They may feel unable to stay out for long periods of time or have to cancel or change plans at the last minute if they feel unwell.

Many IIH sufferers report feeling fatigued, pain itself can be very tiring and draining.

The headaches associated with IIH can be extremely painful and often do not respond to painkillers.

People with IIH often suffer from pulsatile tinnitus which is a "whooshing noise" that is heard in the ears in time with the pulse. It can be a symptom that occurs most of the time. Silence is the worst thing for tinnitus because the tinnitus simply sounds louder. Tinnitus can be extremely distressing especially if it interferes with sleep, sufferers may benefit from listening to music or audio books to aid sleep.

Patients describe the nausea and dizziness they feel as though the room is spinning or rocking, like feeling sea-sick on a boat and their balance problems as though they are 'drunk', or being pushed by an unseen force.

The visual problems associated with IIH can be extremely disabling. Many sufferers with IIH can experience a decrease in visual acuity. IIH sufferers may experience blurred and double vision, lack of depth perception and may find walking around without bumping into things or crossing roads difficult. They may also find reading difficult. Those who suffer from photophobia may find household lights too bright and may want to draw curtains and close blinds, they may benefit from having dimmer switches fitted to lights around the house.

Problems with memory or confusion and disorientation can make it difficult for some sufferers with IIH to go outside alone. They may need help with many everyday tasks which most people take for granted.

As well as the physical symptoms, sufferers also have to cope with the emotional side of the condition, worries about the future and their symptoms.

Depression is quite common in people with chronic health conditions.

Sufferers who experience visual problems may be concerned about worsening vision or losing their vision, though only a small minority of sufferer will suffer substantial permanent visual loss.

Sufferers of IIH may feel frustrated by the limitations of their symptoms. If they have difficulty getting around alone, they may feel isolated and distressed by their lack of independence or frustration and guilt that they have to rely on others to care for them.

### Coping with the treatments

As well as the physical and emotional effects of the symptoms of IIH, sufferers also have to cope with the treatments needed to control the condition. There is currently no cure for IIH and the success of treatment is variable.

Medical treatment can have a variety of unwanted or severe side effects that come with the medications prescribed. Some doctors will only perform lumbar punctures for diagnostic and monitoring reasons, whereas

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some will perform them therapeutically to ease symptoms. Lumbar punctures can temporarily ease symptoms but can be uncomfortable and painful. If lumbar punctures are needed on a regular basis, they can cause long term back pain.

### **Surgical options**

If medical treatment has been tried unsuccessfully, especially if vision is worsening, it may be necessary to consider neurosurgery. There are two main types of shunts used in the treatment of IIH. The lumbar peritoneal (LP) shunt involves inserting tubing into the area of lumbar spine and through to the abdominal cavity to allow excess CSF to drain away. The ventriculo peritoneal (VP) shunt, this shunt is inserted directly in to the fluid filled cavities in the centre of the brain, the tubing is fed down through the neck into the peritoneal cavity. Inserting a VP shunt involves operating directly on the brain, with both types of shunt there are the risks of any surgery, as well as infection and blockage of the shunt. Shunts which malfunction may need to be replaced or re-sited.

For many sufferers with a shunt their symptoms will be eased considerably, however even when a shunt is working properly some IIH symptoms, including headaches can remain.

When a shunt is fitted without a valve, over-draining, which also causes severe headaches, can occur. Sufferers with shunts fitted may not be able to do some physical activities which could damage or dislodge the shunt e.g. contact sports such as judo or rugby and if the shunt has a programmable valve they must be wary of coming in to contact with strong magnets.

### **Carers**

If you are the main carer of someone with severe symptoms of IIH, you also may need support. Caring for someone constantly can be very wearing and tiring, and you too need a break and support. Make sure that you have time for yourself and to go out and meet friends and rest. You may also find it useful to share your experiences with other carers. Information on sources of help for carers and your local carers' association can be found from your local Council, Citizens Advice Bureau or advice centre and on our website and IIH Support forum.