

### Working to relieve the pressure!

Idiopathic Intracranial Hypertension is a rare and often debilitating neurological condition affecting less than 1 in every 100,000 people per year. The statistics for children are even lower.

#### What is IIH?

The space around the brain is filled with a water-like fluid (cerebrospinal fluid). If there's too much of this fluid, the pressure around the brain rises because the space containing the fluid can't expand. It's this high pressure that produces the symptoms of IIH.

#### Symptoms of IIH

The most common symptoms of IIH are: severe headache, papilloedema, transient visual obscuration's (temporary loss of vision), diplopia (double vision) and decreased visual acuity, pulsatile tinnitus ("whooshing noise" in the ears in time with the pulse), pain behind the eye and 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 nonspecific symptoms. Although many sufferers have symptoms in common, each sufferer is an individual and should be treated accordingly.

#### How is IIH treated?

IIH is diagnosed by performing a brain scan, a CT or MRI scan, to check for any abnormalities or masses in the brain, followed by a lumbar puncture to confirm the high pressure.

#### Medical treatment

The most commonly prescribed medication is Acetazolamide (Diamox), a carbonic anhydrase inhibitor used for glaucoma, some types of epilepsy and fluid retention. It reduces CSF production in most patients.

Many patients find that the side effects are reduced in comparison with the standard form. Furosemide, a diuretic, is sometimes prescribed but has been proven to have little effect on raised ICP.

In extreme cases where sight is threatened patients may be treated with a short dose of steroids. Other medications prescribed include Topiramate, Amitriptyline and more. Analgesic's (pain killers) are used to treat the pain associated with IIH, with varying degrees of success. As with all pain killers care must be taken as many can be addictive and some can have severe side-effects.

Some IIH patients are treated with therapeutic lumbar punctures (LPs) to remove excess CSF on a regular basis.

#### Surgical treatment

Surgical intervention is usually only undertaken in severe cases: for example, to protect vision or when medications and other treatments are unsuccessful or not tolerated. There are a range of intervention options which can be read about on our surgical leaflet.

#### Long Term Prognosis

Some patient's symptoms may spontaneously disappear, for others a combination of medical and/or surgical treatments control their condition and they are able to lead relatively 'normal' lives. For others both medical and surgical treatments can be limited in their effectiveness and symptoms may remain. For these patients, treatments with combinations of painkillers and other medications are required to control the symptoms although their effectiveness varies.

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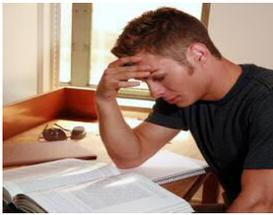
### At school, college or university

Difficulties with concentration, problems with short term memory and fatigue are common. Allowing students to use a note-taker or 'Dictaphone' to record lessons and lectures can help enormously. Methods of teaching may need to be adjusted to accommodate a student's difficulties. It may be better for students if subjects are

broken down into discrete components, as struggling with a complex subject may lead a sufferer to feel overloaded.

The symptoms of IIH can be very severe at times and variable; students will need support to develop coping strategies and to set realistic targets. It helps if educational establishments can be flexible about a student's attendance at all. Sufferers may need to be reminded about deadlines and modular courses staged assessments may be better for students with IIH. Alternative arrangements should be put in place to allow them, within the limitations of their illness, to keep up with their classmates and the requirements of the curriculum.

IIH can cause problems with spatial awareness. Educational establishments can help by allowing sufferers to use lifts if available and allowing extra time to reach classrooms via stairs, or to cross roads on split-site establishments. In addition many sufferers have photophobia so bright light may be painful for them which may need consideration. If there is visual acuity loss, they may need large print hand-outs, or possibly coloured paper or overlays.



Concentration and memory problems can make exams more stressful and special arrangements may be required. It can be easier to accommodate the needs of someone with IIH to take exams in a separate room. Fatigue can mean that the sufferer needs to take a break.

### Friendship

It's important for IIH sufferers to maintain friendships. The condition can be isolating, as sufferers may not have the same social life as their friends and classmates, so schools, colleges and universities should encourage friendships and the development of new friendships. This is particularly important if a student misses a lot of school or college. Friends and classmates may find it difficult to understand what IIH is and the effect that it has on their classmate and it's often helpful if they can be given information about IIH. Perhaps a few closer friends could be encouraged to visit when the sufferer is absent from school.



### IIH and Shunts

Students with shunts can do most things that other children and young people can do, and can take part in sports and other activities. Those with an LP shunt should avoid stretching or twisting exercises and contact sports should be avoided.

If the student receives a blow to the head, back or abdomen, damage to the shunt can occur. If a student complains of headache, dizziness, drowsiness, suffers vomiting or fits, or just doesn't seem to recover well from a blow or a fall, medical treatment should be sought.

Shunts can fail or block and a student may have to be hospitalised for surgery to revise their shunt. The length of hospitalisation and the recovery time needed varies from individual to individual. Even with a fully functioning shunt some people still have severe headaches, fatigue and other IIH symptoms.

Children with IIH may qualify as having a disability due to chronic symptoms. Some may use a wheelchair and need extra help due to fatigue. If a child is on regular medication, the teachers and parents must be aware of when the medication needs to be taken and that the child is drinking enough fluids.

Some IIH sufferer's symptoms are so chronic that they are classed as having a special educational need. The place of Education and the local SEN team must be alerted to the child's condition and be involved with the child's needs whilst under their care

On the following page we have listed useful websites.

**Working to relieve the pressure!**

If your child is having difficulty at school, please take some time to visit these websites. There are some useful websites for schools and colleges too.

**SEN (Special Educational needs) A guide for parents and carers:**

<https://www.education.gov.uk/publications/standard/publicationDetail/Page1/DCSF-00639-2008>

**How to appeal against an SEN decision for parents:**

<https://www.education.gov.uk/publications/standard/publicationDetail/Page1/SEN-APPEAL-2010>

**Access to Education for children and young people with medical needs:**

[http://www.direct.gov.uk/en/Parents/Schoolslearninganddevelopment/YourChildsWelfareAtSchool/DG\\_10037983](http://www.direct.gov.uk/en/Parents/Schoolslearninganddevelopment/YourChildsWelfareAtSchool/DG_10037983)

<https://www.education.gov.uk/publications/standard/publicationDetail/Page1/DFES%200732/2001>

**Disability Tool Kit for Schools:**

<http://www.education.gov.uk/schools/pupilsupport/sen/a0065985/disability-toolkit>

**Benefits**

**Disability Living Allowance:**

[http://www.direct.gov.uk/en/MoneyTaxAndBenefits/BenefitsTaxCreditsAndOtherSupport/Disabledpeople/DG\\_10011816](http://www.direct.gov.uk/en/MoneyTaxAndBenefits/BenefitsTaxCreditsAndOtherSupport/Disabledpeople/DG_10011816)

**Carers Allowance:**

[http://www.direct.gov.uk/en/Parents/Schoolslearninganddevelopment/YourChildsWelfareAtSchool/DG\\_10037983](http://www.direct.gov.uk/en/Parents/Schoolslearninganddevelopment/YourChildsWelfareAtSchool/DG_10037983)

**IPSEA** is a national charity providing free legally based advice to families who have children with special educational needs. All our advice is given by trained volunteers.

<http://www.ipsea.org.uk/>

**Contact a Family** is the only UK-wide charity providing advice, information and support to the parents of all disabled children. Free Helpline: 0808 808 355

<http://www.cafamily.org.uk/>

**Parent Partnership**

Parent Partnership Services (PPS) are statutory services offering information advice and support to parents and carers of children and young people with special educational needs (SEN). PPS are also able to put parents in touch with other local and national organisations.

<http://www.parentpartnership.org.uk/>