

## **IIH and Education**

Idiopathic Intracranial Hypertension (IIH) is a condition where the cerebrospinal fluid (CSF) builds up around the brain. IIH has been known by other names such as Benign Intracranial Hypertension or Pseudotumour Cerebri. It is a condition with an unknown cause or causes.

A diagnosis of IIH can be a shock to both the person diagnosed and those around them. The most common symptoms of IIH include:

- Headaches.
- Visual obscurations
- Pulsatile tinnitus
- Back pain
- Dizziness
- Neck pain

Less common symptoms that are sometimes reported include:

- Blurred vision
- Memory problems
- Nerve pain
- Double vision

People with IIH have also reported:

- Fatigue
- Nausea and vomiting
- Photophobia
- Problems with depth perception, disorientation and slurred speech

Many people with IIH use the term brain fog to describe a feeling of being spaced out and aphasia (difficulty using or understanding words).

Although many people with IIH have symptoms in common, each person is an individual and should be treated accordingly. Some children are often too young to report their symptoms adequately and can present with many non-specific symptoms.

## Medical treatment

Many people can have their IIH 'controlled' via medication. The most commonly prescribed medications are Acetazolamide (Diamox®) and Topiramate (Topamax®) which may need to be taken throughout the day. Side effects include tingling of hands and feet, headache and increased need to urinate, they must be allowed access to toilet facilities as and when needed. It is advisable to encourage students taking these medications to drink plenty of fluids throughout the day and especially after physical education or on hot days.

People who take Acetazolamide have an increased risk of sun burn and should take extra care when the weather is hot and sunny.

Analgesic's (pain medications) are used to treat the pain associated with IIH, with varying degrees of success. Students may need to be given pain medication during the day. This should be recorded by the school and relayed to the parents/carers.

## 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.

People may undergo surgery to have a shunt inserted to divert the flow of excess CSF.

## Surgery types

A *Lumbo-peritoneal (LP) shunt* is inserted in the lower back, the “lumbar region” of the spine. The proximal catheter is carefully placed in the space between the spinal cord and spinal nerves which is filled with cerebrospinal fluid. Tubing from the proximal catheter drains excess CSF into the peritoneal cavity (The peritoneal cavity is a fluid-filled gap between the walls of the abdomen and the organs in the abdomen).

A *Ventricular Peritoneal (VP) shunt* the proximal catheter is inserted directly in the ventricles of the brain. A valve is attached to the proximal and distal catheters. The distal catheter is placed in the peritoneal cavity.

A *Ventriculoatrial (VA) shunt* the proximal catheter is inserted directly in the ventricles of the brain. The distal catheter lies within the right atrium of the heart.

*Venous sinus stenting* is also used as a surgical procedure for adults with IIH who have Venous Sinus Stenosis. Stent surgery is performed after various investigations. If the patient is a good candidate, a stent is

placed within the venous sinus and dilated which can result in the reduction of pressure and relieve symptoms.

*Intracranial Pressure (ICP) Monitoring* involves a surgeon drilling a small hole in to the patients' skull and placing an intracranial pressure catheter on to the brain tissue surface to record CSF pressure. When placed it senses the ICP inside the skull and sends its measurements to a recording device, which then displays the pressure reading on the monitor at the bedside.

*Lumbar Puncture (LP)* is the insertion of a needle into the cerebrospinal fluid, (CSF) within the spinal canal. This fluid surrounds the spinal cord and the brain, and in part acts as a shock absorber, protecting the delicate structures that make up the central nervous system. It is termed a "lumbar puncture" because the needle goes into the lumbar portion (the "small") of the back.

Students with shunts can do most things that other young people can do, they can take part in sports and other activities, symptoms allowing. Those with an LP shunt should avoid stretching or twisting exercises and contact sports should be avoided. If the student has a LP, VP or VA shunt they should avoid contact sports. 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 due to the possibility of shunt damage.

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

### Long Term Prognosis

Some peoples IIH symptoms spontaneously disappear. Others may have to undergo a combination of medical and/or surgical treatments to control their condition allowing them to lead relatively 'normal' lives. For others both medical and surgical treatments can be limited in their effectiveness and many debilitating symptoms may remain. For these people with IIH, treatments with combinations of pain and other medications are required to control the symptoms although their effectiveness varies.

### At school, college or university

Some students with IIH may have Special Educational Needs due to their symptoms and possible disabilities. Inclusion Leaders should be

advised about any student with IIH attending an educational establishment.

A care plan should be drawn up by the Inclusion Leader and parents/carers to ensure that all the staff are made aware of the student's difficulties, symptoms and action needed. Educational establishments should be flexible about a student's attendance as the symptoms of IIH can be variable and very severe at times.

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. Students may need to take a break or have some quiet time during lessons.

Some schools offer an exit pass to students which allows them to leave the classroom during lessons should they become unwell.

If older students are struggling with the workload they may find that dropping subjects will help them cope better. Some people with IIH find that they feel worse in the morning so starting school later in the morning may help them too.

## Eyesight

IIH can cause visual field defects and problems with spatial awareness and depth perception. Educational establishments can help by allowing students with IIH to use lifts, if available, and allowing extra time to reach classrooms via stairs, or to cross roads on split-site establishments. Placing coloured strips on edges of steps and stairs can help students determine the depth.

Some may suffer with photophobia. Bright light may be painful for them which may need consideration. If visual acuity loss has occurred, students may require large print handouts, or possibly coloured paper or overlays.

## Confusion and stress

Some people with IIH can feel overwhelmed in a busy environment. Noises and people can cause distraction, feelings of being overwhelmed by a task, confusion as to what they are being told or asked to do. Allowing older students to use a note-taker or 'Dictaphone' to record lessons and lectures can help enormously. Students will need support to develop coping strategies and to set realistic targets. 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 anxious and overloaded.

## Hearing sensitivity

Some people with IIH may have problems with hearing. At times they might not be able to hear as well as they should. On days like this a student should be asked if they want to be closer to the front of the class so they can hear the teacher. Other times hearing can be over sensitive, loud play grounds, lunch halls, music lessons etc. can be overwhelming and the student should be given the option to leave the area.

## Exams and tests

It can be easier to accommodate the needs of someone with IIH to take exams in a separate room. Concentration and memory problems can make tests and exams more stressful and special arrangements maybe required to allow students to rest or take a break.

Special Consideration is a post examination adjustment to a candidate's mark or grade to reflect temporary injury, illness or other indisposition at the time of the examination/assessment. Details of these can be found on the JCQ website: <http://www.jcq.org.uk/exams-office/access-arrangements-and-special-consideration>

## Home Tutoring

The Department of Education statutory guidance states that ‘Local authorities (LAs) must have regard to statutory guidance when carrying out their duty to arrange suitable full-time education (or part-time when appropriate for the child’s needs) for children who are unable to attend a mainstream or special school because of their health’.

LAs are responsible for arranging suitable full-time education for permanently excluded pupils, and for other children who – because of illness or other reasons – would not receive suitable education without such provision. This means that where a child cannot attend school because of health problems, and would not otherwise receive a suitable full-time education, the LA is responsible for arranging provision and must have regard to this guidance.

If a child is off sick for longer than 3 consecutive weeks some LA’s will provide a home tutor for approximately 5 hours a week. Other LA’s may be able to arrange home tutoring much sooner and for longer. Each LA has a different approach to providing education for pupils who cannot attend due to health issues. It is important for Inclusion Leaders to communicate with parents/carers about the options available in their area.

Many hospitals provide teachers and schooling for children who are in hospital. Work undertaken is usually sent home with the child on discharge and could count towards class work.

Full guidance can be found here: <http://www.education.gov.uk/aboutdfe/statutory/g00219676/health-needs-education>

## Friendships

It is important for students with IIH to maintain friendships. The condition can be isolating, as they may not have the same social life as their friends and classmates. Friendships should be encouraged. This is particularly important if a student misses a lot of school or college due to hospital stays and recovering from operations, medical appointments or days off due to illness. Friends and classmates may find it difficult to understand what IIH is and the effect that it has on theirclassmate. It's often helpful if they can be given information about IIH. Sending cards signed by the class to younger students in hospital or offsick can lift their spirits and make them feel more included.

## Disabled students Allowance

Some students applying for undergraduate or postgraduate education may be able to apply for Disabled Students' Allowances (DSAs) to cover some of the extra costs they have because of the problems

associated with living with a long term illness. This will depend on how the condition affects them. They can get the allowances on top of their other student finance and will not need to repay DSAs.

Find more information about DSA here: <https://www.gov.uk/disabled-students-allowances-dsas>

Useful links:

SEN (Special Educational needs) overview for parents/carers and carers:

<https://www.gov.uk/children-with-special-educational-needs/overview>

How to appeal against an SEN decision for parents/carers:

<https://www.gov.uk/special-educational-needs-disability-tribunal>

Increasing options and improving provision for children with special educational needs (SEN) <https://www.gov.uk/government/policies/increasing-options-and-improving-provision-for-children-with-special-educational-needs-sen>

SEN Guidelines for schools <https://www.education.gov.uk/childrenandyoungpeople/send>

SEN Guide for parents/carers <https://www.gov.uk/government/publications/send-guide-for-parents-and-carers>

### Other useful websites:

IPSEA is a national charity providing free legally based advice to families who have children with special educational needs. All 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/carers of all disabled children.

Free Helpline: 0808 808

355

<https://contact.org.uk/>

I want to  
know more  
about IIH....

Where can I get more information?

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

Write notes here:

A team of people contributed to this leaflet. It was written IIH UK Trustees. It was assessed in the draft stage by the IIH UK Team. It was reviewed by a group of parents whose children have IIH. Michelle Williamson is responsible for the final version. The views expressed in this leaflet are of the authors.

Please note we have made every effort to ensure the content of this is correct at time of publication, but remember that information may change. This information leaflet is for general education only.

The logo for IIHUK features a stylized green 'X' shape on the left, followed by the letters 'IIHUK' in a bold, blue, sans-serif font. Below this, the full name 'Idiopathic Intracranial Hypertension' is written in a smaller, grey font.  
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