

Patient information

Idiopathic Intracranial Hypertension (IIH) in Children

What is IIH?

Idiopathic Intracranial Hypertension means excessive pressure from Cerebrospinal fluid (CSF) within the skull with no known cause.

Basic anatomy of the brain and CSF

CSF is one of three major components within the skull; the other two are the brain itself and the blood vessels to the brain. Normally, these three components work together in a delicate balance, but since the skull itself can not expand, an increase in volume of any one of these components results in pressure being exerted on the other two.

CSF has several important functions. It cushions the brain within the skull, helps to transport essential nutrients to our brain, and carries waste products away. There is a complex system of interconnecting spaces (ventricles) within our brains where our CSF flows, as well as surrounding our entire brain and spinal cord. When our body can not effectively absorb or drain our CSF, the pressure within our skull (intracranial) increases.

What are the causes of IIH?

IIH is rare and can occur at any age, but is more prevalent in women and teenagers of reproductive age who are overweight or obese. Obesity is the leading cause of IIH in teenagers and adults.



Children who present with IIH are a special group. The incidence of IIH in children is approximately 1 in 100,000, which is similar to the adult population, but there is an equal distribution between girls and boys under the age of 10 years.

Secondary causes of IIH include hormone imbalances and the use of hormone therapy, some medications (e.g. antibiotics and thyroid replacement therapy), blood clots within the brain (venous sinus thrombosis), meningitis, severe anaemia and systemic diseases such as Lupus, Lyme's disease and sarcoidosis.

What are the symptoms of IIH?

Most people with IIH generally experience

- Severe throbbing headaches. These are often constant, worse in the morning, aggravated by straining or coughing, associated with nausea and vomiting and are sometimes relieved by standing up. Night time headaches may also be present.
- Double vision and other vision changes. The pressure within the skull causes the optic nerves to swell (known as papilloedema) which can cause blurred, and even loss of, vision. If left untreated, the damage may result in permanent visual impairment.
- Tinnitus. This is typically a pulsating, rhythmic sound that you can hear in your ears.
- Tiredness.
- Neck pain.
- Mood and behaviour changes.
- Difficulty sleeping.

How is IIH diagnosed?

A doctor will discuss your symptoms with you and your parents or carers. Your doctor will first need to rule out any other causes for your symptoms. They may look at your eyes too. If they suspect IIH, you will be referred to a special eye doctor called an Ophthalmologist for a detailed examination. You may also see a special doctor called a Neurologist, who may ask for you to have a CT or MRI scan. You may have to have some blood tests and a Lumbar Puncture (LP) to measure the pressure and test your CSF. These tests all help to diagnose IIH and will require you to visit the hospital for appointments.

How is IIH treated?

If you are overweight, it is important to lose weight. You may be referred to a dietician or obesity clinic to support this. Losing weight often relieves symptoms altogether, with no need for medical treatment.

You may be given medication to ease the symptoms. Medications such as acetazolamide and topiramate may be used to reduce the production of CSF. A diuretic (furosemide) can be used to help remove excess fluid from the body. Steroids (prednisolone) help to reduce swelling. Various painkillers may also be used to relieve headaches. Treatment with medication can work well with some people, however all medications have the risk of side effects.

Surgery is considered as a last resort for the treatment of chronic IIH. Surgery usually involves meeting a Neurosurgeon and being assessed.

What is the prognosis for IIH?

It is important to detect IIH early and start treatment to prevent permanent loss of vision.

Many patients with IIH find their symptoms improve with weight loss and/or medication therapy. It is important to know that IIH affects everyone differently, and does not mean that you will need to stop going to school or participating in your hobbies and activities. It just means looking after yourself and recognising when to take it easy.

It can also be hard for others to understand how you are feeling as much of the time people with IIH may not look 'sick'. Your Neurology Nurse Specialist will be able to provide you with further information and support on living with IIH.

Useful Contacts:

Paediatric Neurology Clinical Nurse Specialist:

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Patient Advice and Liaison Service

If you need general information or advice about Trust services, please contact the Patient Advice and Liaison Service (PALS) on 020 3594 2040 or visit www.bartshealth.nhs.uk/pals. Alternatively please contact staff who are providing your care if you require clinical advice.

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