

## Become a member of IIH UK today!

Being a member of IIH UK not only shows your support but also provides you with access to our members' newsletter, benefit help guides and priority booking at our annual Patient Conference and AGM. IIH UK is solely funded by fundraising, donations and membership fees and with fees starting at just £5 per year, your membership really does make a difference.

Membership can be purchased from our online shop.

[www.iihukshop.moonfruit.com](http://www.iihukshop.moonfruit.com)



IIH UK is funding IIH research! We are working with our Patron Dr Alex Sinclair and her team of clinicians in Birmingham clinical trials; it has never been a better time to join us.

## Visit our website [www.iih.org.uk](http://www.iih.org.uk)

Record your IIH medication and shunt details on our handy Medical Condition Card



Our website features links to:

- Current research
- IIH Support UK Fb group
- Weight loss support group
- Employment support group
- UK wide regional groups
- IIH Group for men
- Fundraising ideas
- Medically verified information Leaflets

Visit our online shop for IIH Awareness, merchandise, clothing, membership and more!

Why not download a fundraising ideas pack and organize your own fundraiser?

Join an IIH UK Social group in your area through Facebook and meet other people with IIH.

This leaflet is provided to assist people with IIH and those who care for them to understand their condition, and not to offer medical advice. Always consult your doctor regarding treatment and medical advice. IIH UK does not endorse nor recommends any products or treatments mentioned in the leaflet.



(Previously known as Pseudotumor Cerebri or Benign Intracranial Hypertension)

## Working to Relieve the Pressure!

Have you been diagnosed with IIH or care for someone who has? At IIH UK we understand how overwhelming it can feel.

## We can help by offering;

- Contact with other people with IIH
- Information
- Non medical advice
- Support

**National Charity 1143522  
Scotland SCO43294**

 [www.facebook.com/IIHUKCharity](http://www.facebook.com/IIHUKCharity)

 @IIHUK

 [info@iih.org.uk](mailto:info@iih.org.uk)

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

## What is IIH

Idiopathic intracranial hypertension (IIH), also known as Benign Intracranial Hypertension or pseudotumour cerebri, is a condition with an unknown cause or causes. The condition is associated with raised fluid pressure around the brain. The fluid that cushions the brain is called cerebrospinal fluid (CSF).

It can cause disabling daily headaches and visual loss, which can be permanent. The raised brain pressure can press the nerves supplying the eye (also known as papilloedema) and this can affect vision.

The commonest 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

Read the consensus guidelines on IIH management here:

[www.jnnp.bmj.com/content/89/10/1088](http://www.jnnp.bmj.com/content/89/10/1088)

## Treatments available for IIH

The majority of people will have medical (drug) treatment for IIH and headaches. Less than 1 out of 10 people with IIH will have surgical treatment.

Medical treatments for IIH have been assessed by a medical review body (the Cochrane review) and they have suggested that more trials are required to understand what are the best drug and surgical treatments for IIH. Acetazolamide (Diamox™) is often prescribed for IIH.

There are no drugs specially designed for IIH headaches.

9 out of 10 people with IIH are overweight and weight loss has been proven to be the most effective treatment. For further information on weight loss see the IIHUK Weight and IIH leaflet.

There is evidence that weight loss improves headaches in IIH.

(Newborg 1974; Koppersmith 1998; Johnson 1998; Sinclair 2010).

Your health care professional may use medications to help with the headaches. For further information on headaches see the IIHUK Headache in IIH leaflet available on our website.

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

## Living with a diagnosis of IIH

A diagnosis of IIH can come as a shock to both the person diagnosed and those who care for them. For some people it can be a life changing condition whilst for others medication and if recommended, weight loss can cause IIH to go into remission.

Some people recover spontaneously after their first lumbar puncture. Some manage well with medical and/or surgical treatments whilst some may go on to suffer chronically even with treatments, which can be extremely debilitating for that person.

IIH is invisible from the outside. It is hard for those watching on to understand what a person with IIH is feeling or experiencing. For those suffering it is frustrating having to explain how they are feeling as they often look 'well'. Caring for someone with IIH can be demanding and carers will need support as well as those with IIH.

Our Facebook support group at IIH Support UK is designed for those with IIH and all who care for them. Run by volunteer IIH patients and carers it is a place to exchange experiences, hints and tips on coping with symptoms and be supported by those who know what you are going through.

[www.facebook.com/groups/432155240173972/](https://www.facebook.com/groups/432155240173972/)