

Information for friends, family and carers

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. (Read the 'What is IIH' leaflet for further information)

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

Although many people with IHH 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. (Contact us if you have a child under 16 with IHH and we can put you in touch with a parent Facebook group)

Coping with the symptoms

IHH is an invisible condition and for those watching it is hard to understand what the person feels or is experiencing. For the person with IHH the symptoms can be extremely debilitating and disabling. That said, IHH affects everyone differently, some may have more severe symptoms than others and their ability to participate in social, domestic or work activities can vary. 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. Some people with IHH report feeling fatigued, pain itself can be very tiring and draining and may be associated with anxiety and depression. IHH pain is not like any headache you may have experienced and often does not respond to painkillers.

People with IHH 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. It can be extremely distressing especially if it interferes with sleep, IHH patients may benefit from listening to music or audio books, relaxation techniques have also been found to help aid sleep.

Patients describe the nausea and dizziness they feel as though the room is spinning or rocking which is similar to the feeling associated with sea sickness. People with IHH have reported that they are sometimes mistaken of being drunk due to their problems with balance, confusion and slurred speech.

The visual problems associated with IHH can be extremely disabling. 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. Having IHH can severely affect vision so it is vitally important that people with IHH seek medical advice if their vision changes.

Living with IHH

Due to the varying symptoms that a person with IHH can experience it may be difficult for them to achieve everyday activities or tasks safely, including going out alone and may need help or supervision. They may become frustrated by the limitations of their symptoms and may feel isolated, distressed and become anxious by their lack of independence; they may also feel guilt that they have to rely on others to care for them. As well as the physical symptoms, people with IHH 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. (See the depression leaflet)

Positive focus

Many people with IHH have told us that the constant hospital appointments, side effects from treatments, being unable to work and filling in benefit forms can all be a negative experience and they will require your support to keep a positive focus. Doing something fun after an appointment or treatment like

watching a favourite film together or having a carpet picnic, are all ways to help them keep a positive focus which in turn will help them become more able to cope with living with IIH.

Carers

Caring for someone with IIH can be very wearing and tiring both emotionally and physically and carers may also need support. Ensure that you make time for yourself, rest or go out and meet friends. You may also find it useful to share your experiences with other carers. Your local council will be able to help you find sources of help in your area such as your local carers' association, your local Citizens Advice Bureau are also a good source of information.

Where can I get more information?

IIH UK website: www.iih.org.uk

IIH UK Support Group: <https://www.facebook.com/groups/432155240173972/> Find your local Council: <https://www.gov.uk/find-local-council>

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 patients who have IIH. Clare Parr 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.



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