

Headaches in Idiopathic Intracranial Hypertension

Headache is the most common symptom in patients with Idiopathic Intracranial Hypertension (IIH). Not everybody with IIH gets headache.

- Headaches can be there every day.
- They can be disabling.
- They can reduce people's enjoyment and quality of life.
- Headaches happen for many reasons.
- People with IIH may suffer from more than one type of headache.
- Headaches may be severe, and this may not be linked to your brainpressure.
- Headaches may continue even when your brain pressure settles.

There many ways to treat headache. There are a number of different headache types that people may suffer from as part of their IIH.

A number of different headaches can happen together in IIH, such as:

- Headache caused by IIH
- Migraine
- Medication overuse headache (MOH)
- Tension-type headache

It is often difficult for people to tell what types of headaches they have. This is because different types of headaches can feel the same. This leaflet will talk about these type of headaches.

What is headache caused by IIH?

High brain pressure can trigger headaches. A diagnosis of IIH would need to be made by a specialist healthcare professional for this headache. Almost all people with IIH have swollen eye nerves called papilloedema at diagnosis. They may also have pulsatile tinnitus (whooshing sound in the ear). Pulsatile tinnitus also occurs in migraine and other conditions.

IIH without papilloedema, is a rare condition where high pressure can trigger headaches but in this condition at diagnosis there is no papilloedema.

(see IIHWOP leaflet).

The headache may happen every day or less often. Some IIH headaches improve after lumbar puncture (but migraine headaches can also improve after lumbar puncture). It may be worse in the morning, on bending and on coughing (but other headaches can have these too). The exact feeling of these headaches is not well described, and vary considerably between people.

How do you treat headaches caused by IIH?

There are no drugs specially designed for IIH headaches. There is evidence that weight loss improves headaches in IIH (Newborg 1974; Kuppersmith 1998; Johnson 1998; Sinclair 2010).

What is Migraine?

Migraine headaches often happen in IIH. Migraine headaches are often on one side of the head but can spread over both sides. They can cause neck and shoulder ache.

The pain might be severe and pulsating or throbbing. Any head movements may make this worse. They can last a long time (many hours to days) and can happen every day.

If the migraine attacks happen on less than 15 days a month this is called episodic migraine. If they happen on more than 15 days a month this is called chronic migraine.

How do migraines make people feel?

Migraine headaches can make people feel sick, and sometimes vomit. They often want to avoid bright lights, loud noises and moving. Many people want to lie down in a dark quiet room. After the attack is over they can feel tired and washed out.

Warning signs of migraine.

Before the headache some people know when it is about to happen as they experience “Aura”. Aura can be changes in your vision such as seeing coloured or bright lights, lines, zig-zags, looking through frosted glass or steaming windows or just blurring of the vision. It does not last long (usually around 20 minutes, but can be longer).

Other types of aura include difficulty getting words out, tingling in the face/hands/legs and even difficulty moving. This can be frightening. If this has not happened before it is important to see a doctor.

What can I do for my migraine type headaches?

There are various ways to manage migraine. Life-style advice, avoiding medication over use headaches, migraine painkillers and prevention tablets may be helpful. More detail on medication over use headaches is written below.

What life-style advice is helpful in migraines?

Changing lifestyle can be helpful for migraines. Consider reducing caffeine if you take too much. It may be helpful to have regular meals and water. Gentle regular exercise and regular sleep habits help some people. Some people find yoga and mindfulness can help.

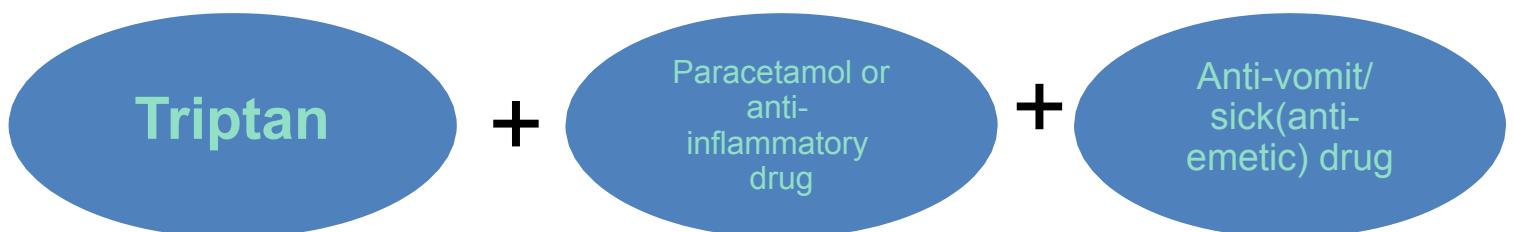
For more information see the Migraine Trust website www.migrainetrust.org

What are migraine painkillers?

These are tablets that are to be taken as soon as the headache starts to provide immediate pain relief. It is best to avoid opiate or codeine based tablets (such as morphine, codeine, tramadol etc.) Migraine painkillers are often from the family of triptan drugs.

Tips on using migraine pain killers.

- Some work faster than others, some last longer than others.
- Take the pain killer early when the attack starts.
- Try the pain killer at least three times before deciding if it helps you.
- Only use x2 a week.
- Current guidelines from National Institute of Health and Clinical Excellence (NICE) suggest taking triptans with a simple pain relief tablet (e.g. paracetamol or non-steroidal anti-inflammatory tablet such as brufen) and often with an anti-sickness tablet:



These drugs can be given in many ways. They can be tablets to swallow. They can be melts under the tongue or a nose spray. They can be injected or used as a suppository.

If the first or following triptan tablets do not help reduce the headache, then ask your doctor to try another type of triptan.

These medicines should only be taken twice a week for migraine attacks, so it's best to save these for the most severe attacks. If you feel you need to take these more than twice a week, talk to your doctor about starting a prevention tablet.

Prevention drugs for migraine type headaches

They are many different types of prevention drugs that can be given. Your doctor will help find the one that suits you best.

Tips for starting migraine prevention drugs

- Start at a low dose.
- Slowly build up the correct dose as recommended by your doctor.
- It can take 3-4 months for the medicine to start to work.
- A diary of how often you get your headaches will help your doctor (migraine diary).
- Prevention medicines will not work well if you also have medication overuse headaches.

What about becoming pregnant?

- If you are considering becoming pregnant, tell your doctors as many of the drugs potentially can harm the unborn baby.

I take the pill (oral contraceptive), what do I need to know?

- Some drugs can affect how well the oral contraceptive pill works, so you could be at risk of becoming pregnant. Tell your doctor if you take oral contraceptives.

What are medication overuse headaches?

These are headaches caused by taking pain killers too much. Using pain killers on more than 2-3 days a week for too long a time can make headaches worse. Medication overuse is common and affects approximately 2% of the world's population. IIH patients are often affected by this type of headache. Your brain gets used to taking painkillers, and on the days when you try not to take them, the headaches are worse. It is a no-win situation.



Headaches in IH

What causes medication overuse headache?

Any painkiller can cause it. These include Codeine, Co-codamol, Co-dydramol, Paracetamol, Ibuprofen, Panadol, Anadin extra, tramadol, morphine and more. It includes all painkillers you buy yourself from a shop or pharmacy or any painkillers your GP, Accident & Emergency or other doctor has prescribed for you. It happens quicker with codeine or opiate based drugs.

Why is Medication overuse headache a problem?

It can turn an occasional headache into a chronic daily headache or make an existing daily headache worse. It also makes migraine prevention tablets work less well.

What should I do if I think I have medication overuse headache?

Do not feel bad that this has happened. This is not your fault. It happens to lots of people. It can come on gradually over time. Often no one has warned you this may happen. In fact, many doctors who do not treat long term headaches may not have heard of this.

How do I get rid of my medication overuse headache?

See separate leaflet available for medication over use headache and how you can manage this.

What is Tension-type headache?

Tension headache is the most common headache type. This is the headache that we consider as the normal or every day headache.



Headaches in IIH

What does Tension-type headache feel like?

This may feel like a constant pain that can affect both sides of the head. Sometimes the neck muscles might feel tight and a feeling of pressure behind the eyes.

This is not a severe headache and people often continue with their everyday activities. It can last for minutes to hours or days. People often take simple pain relief for these headaches. Be careful with the amount and frequency you take pain killers to avoid of pain relief medication overuse headache. Other way to treat these headaches are lifestyle changes (e.g. exercise, mindfulness, yoga, massage, application of warm flannel to the head or neck). In the context of IIH your health care professional will consider other headache types first, like the types described above.

Write notes or questions for your appointment here:

Where can I get more information?

IIH UK website: www.iih.org.uk

Migraine Trust:

www.migrainetrust.org/Email:

info@iih.org.uk

Registered Charity Number in England & Wales 1143522. Scotland SC043294



A team of people contributed to this leaflet. It was written by H. Lyons. Critically reviewed by S. Mollan and A. Sinclair. It was assessed in the draft stage by the ophthalmology nursing team at University Hospitals Birmingham (UHB). It was reviewed by a group of patients who have IIH, and also assessed by friends and family that attended the Joint IIH clinic at UHB. S Mollan is responsible for the final version. The views expressed in this booklet are of the authors and not their employers or other organisations.

Please note we have made every effort to ensure the content of this is correct at time of publication, but remember that information about drugs may change. This information booklet is for general education only and does not list all the uses and side-effects associated with drugs.

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