

## What is Idiopathic Intracranial Hypertension?

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.

When the brain pressure is high, the majority of people will have eye (optic) nerve swelling called papilloedema. There is a rare type of IIH where there is no papilloedema called Idiopathic Intracranial Hypertension without papilloedema (IIHWOP). See IIHWOP information leaflet.

There can be a number of reasons why someone with IIH has headache. The headache or neurology team may ask several questions to help work out how many different types of headache someone with IIH has.

Headaches can be different between people and can last from hours to days. They can have symptoms that cause problems with the vision and or noises in the ears. There is typically no one location where the headache occurs.

Painkillers for headaches that can be bought from shops or that are prescribed by doctors can if taken for long enough can cause more headache, or mask (hide) the true headache type; this is called medication overuse headache (MOH). This booklet will help you to understand what Medication Overuse Headache is and how you may manage it.

## **What is Medication Overuse Headache (MOH)?**

When people have a bad headache, they take painkillers or are prescribed pain killers. Even though they might have been prescribed these from a doctor and be taking the painkillers as instructed at the correct dose, over time, regular use can result in MOH.

This is a common problem when treating headaches and you should not feel it is your fault. This can happen gradually as headaches get worse, and you may not have been warned of MOH.

## **How common are MOH?**

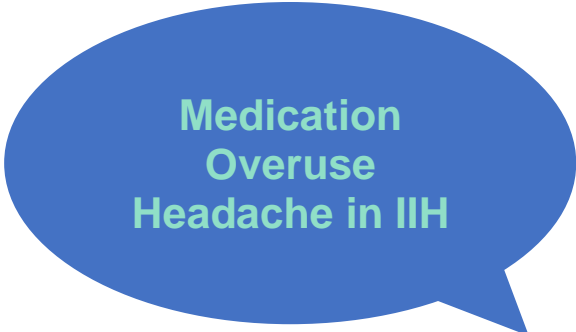
Medication overuse headaches affect 1 in 50 people and is more commonly seen in females in their 30s. It is most commonly seen in patients that use triptans and painkillers, especially opioids, to treat migraines and tension headaches.

## **How do I distinguish MOH from other headaches?**

Patients with MOH find it is more painful in the morning and after exercise. They describe it as a “dull ache”.

You are more likely to be suffering from MOH if you have the following:

- You have been regularly using painkillers to treat headache for the past three months
- Headache goes away once you have completely stop using the painkillers (after months)



- Headache is experienced for at least 15 days of each month
- You can only get a certain diagnosis of MOH if the headaches disappear within two months of stopping the painkillers.

### **Which painkillers can cause MOH?**

All painkillers can cause MOH if taken more than two days a week. Examples are shown in the box below.

Paracetamol, Paramol, Panadol, Panadol extra. Aspirin, Anadin, Anadin extra Ibuprofen, Neurofen, Neurofen extra, Neurofen plus Migraine pain relief, Supermarkets own pain relief, Paramax, Migraleve, Migramax, Naproxen, Diclofenac, Voltarol, Indometacin, Tolfenamic acid, Mefenamic acid, Cocodamol, Codydramol, Codeine phosphate, Dihydrocodeine, DF118, Kapak, Zapain, Tramadol, Tramacet, Morphine, Buprenorphine, Fentanyl, Pethidine, Sumatriptan, Imigran, Naratriptan, Naramig, Frovatriptan, Migard, Rizatriptan, Maxalt, Zolmitriptan, Zomig, Eletriptan, Relpax, Almotriptan, Almogran.

### **How does taking painkillers cause MOH?**

If you suffer from regular headaches, you might end up taking painkillers more frequently. Over time, your body gets used to them, so the effects of the pain relief wears off more quickly, requiring you to take another dose. This results in a cycle of taking pain relief as a result of the worsening headaches. You can find yourself taking them every day.

## **How do you treat MOH?**

1. You *must stop all* painkillers (analgesics) and triptans for 8 weeks. This includes analgesics that were prescribed by your doctors and ones you buy yourself.
2. If you are on high dose opiates, you must see your doctors for more detail on how to withdraw the opiates.
3. Make lifestyle changes: improve your diet and, if possible, take regular exercise, swap caffeinated drinks for de-caffeinated, find ways to reduce stress (visit [www.mentalhealth.org.uk](http://www.mentalhealth.org.uk))
4. You might experience nausea and vomiting when you withdraw your medication; if this happens, visit your doctor for a prescription of anti-sickness tablets. Ensure you tell your doctor other medical conditions, such as heart problems (arrhythmias), as not everyone can use anti-sickness tablets.

## **What support should I have when I'm withdrawing?**

Your family and friends should try and support you as much as they can as withdrawing is a difficult time. Help with the housework and childcare can give you time to focus on dealing with the withdrawal while reducing your stress levels.

You may feel like you need some time off work as headaches tend to get worse before they improve. It is a good idea to discuss this with your manager, so they are more understanding of your condition.

## **How will I feel when I withdraw the medication?**

In the first few weeks of withdrawal, your headaches are likely to worsen. Typically, it takes 8 weeks for your brain to adjust, where you will see an effect. The ultimate goal is to have days where you have no headache or a significantly less severe headache.

## **Are there any complications of MOH?**

The most common problems you may face when you withdraw are headaches. Consult your GP for anti-sickness tablets if you are feeling sick. Low mood and anxiety are a normal response to pain and will improve as your headaches improve. See your GP if they are significantly affecting your quality of life.

## **How can I ease the pain of withdrawal?**

Coming off pain relief can seem daunting but there are other methods which you can try. Ice/heat packs, massages, anti-inflammatory gels and 4head stick may prove useful. Acupuncture is an alternative method.

## **How will my sleep be affected on withdrawal?**

You might find that it is harder to sleep at night. Your GP may prescribe a short course of sleeping tablets or amitriptyline, if you have no other medical problems. It is not recommended you use these long term as they can be addictive.

## **Can I drive while I am withdrawing from painkillers?**

There are no limitations to driving while you are withdrawing from your medication. However, driving is discouraged if you are experiencing a severe headache, visual disturbances, or are generally feeling too unwell to drive.

## **Are there any medications I can have to reduce the pain of withdrawal?**

There are long-term headache preventative medications if you also have migraine headaches that can be taken while you are withdrawing from painkillers however they take time to work (3-4 months) and each have a side-effects. You can discuss this with your doctor.

## **How can I prevent MOH developing again?**

1. If you are taking triptans, do not use them for more than 10-12 days per month.
2. Do not use any form of painkiller for more than 2 days a week, whether it is simple (such as paracetamol or brufen), a triptan, or a combination.
3. Avoid using codeine or other opiates for symptomatic relief of your headaches. This includes mixed opiates such as cocodamol, codydramol, codeine phosphate. Sometime shop bought painkillers contain codeine or caffeine - avoid these.
4. Avoid caffeinated drinks as this affects the absorption of the painkillers and can result in MOH.

5. Remember that painkillers you take for other chronic pain conditions can make your headaches worse.
6. If you find that you are increasing your painkiller intake to over 10-12 days a month, speak to your doctor.
7. Keep a diary of the dose of painkillers you take, and how frequently you take them. Also write down the severity of the headaches (such as 0 no pain to 10 the worst pain). This way it will be easier to spot MOH if you are taking analgesics more frequently while your headaches are increasing in severity.

**Write notes for your appointment here:**

## **Where can I get more information?**

IIH UK website

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

[www.migrainetrust.org](http://www.migrainetrust.org)

A team of people contributed to this booklet. It was written by R. Farwana. 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 assessed by friends and family that attended the Joint Idiopathic Intracranial Hypertension clinic at UHB. It was critically reviewed by the IIHUK trustees. 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 the condition and drugs may change. This information booklet is for general education only.

For full details see the information leaflet that comes with the medicine.

Version 3.0 (11<sup>th</sup> December 2019). Review within two years from publication.