

Cluster headache [CH] is one of a group of headaches known as trigeminal autonomic cephalalgias [TACs]. It is a primary headache [a headache in its own right, not caused by or a symptom of another illness] that causes severe, debilitating pain. It is generally considered to be the most painful medical condition known to mankind and most female sufferers describe the pain as being worse than childbirth. The pain is usually focused around the eye socket/temple, sometimes spreading to other parts of the head like the ear, jaw, forehead and neck. The pain is usually on one side of the head, although it can switch sides between attacks, and rarely can change sides during an attack. At present it is a lifelong incurable condition.

Sufferers usually, but not always, experience one or more of the following symptoms during an attack:

- Reddening and watering of the eye
- A runny or blocked nostril
- Drooping/swollen eyelid
- Constriction of the pupil
- Flushing and facial sweating
- Restlessness/rocking/pacing up and down/extreme agitation

The disease takes two forms, episodic and chronic. In episodic CH attacks occur on a daily basis over a period of weeks or months and then stop as suddenly as they started and go away for a period of weeks, months or even years, but they will return. In chronic CH, the attacks occur regularly with a painfree remission of less than four weeks in any twelve month period.

In most episodic sufferers the headaches start at the same time of year and occur at the same time during the day or night. Each attack typically lasts between 15 minutes and 3 hours (or more) if untreated and can occur up to 8 times a day. It is common for sufferers to experience an attack within 30-90 minutes of falling asleep, napping during the day is not recommended.

So you now know what the nature of the beast is, what are the next steps? The first two things you should look at getting are a correct prescription of drugs, both abortive (painkilling) and preventive; and referral to a headache specialist neurologist. Whether you have been diagnosed by a GP or if you have diagnosed yourself after doing research on your symptoms and taking our '[Do I have Cluster Headache?](#)' test, you should ask your GP for an urgent referral to a headache specialist neurologist for an official diagnosis.

The first line abortive for cluster headache is subcutaneous (injectible) sumatriptan. There are two types; Imigran or the generic Sun Pharmaceuticals version. The other abortive is high flow oxygen. The injections aren't as scary as they sound, they come with a kit and a pen injector, you don't even see the needle – you hold the pen to your leg and push a button and the injection is delivered

in seconds; you feel a slight sting but this is nothing compared to the pain of a CH attack.

Occasionally GPs will try to prescribe the sumatriptan tablets for you - they're cheaper than the injections – but the tablets simply are not strong enough to deal with the pain of CH can take up to 30 minutes to start working, if they work at all. The injections can abort an attack in 8 – 10 minutes. There are also nasal spray versions of this drug but they take longer to work than the injections and are not always effective since most sufferers have a runny or blocked nostril on the affected side.

There are two types of oxygen therapy, standard high flow oxygen and demand valve oxygen. In England and Wales for your GP to prescribe high flow oxygen you need to go to the [downloads section](#) of the OUCH website and download the Home Oxygen Order Form (HOOF). This is part completed ready for a cluster headache sufferer. But before ordering oxygen for you, the GP needs to complete a Home Oxygen Consent Form, and an Individual Home Oxygen Risk Management Form; both these forms will be at the doctor's surgery. Your GP needs to complete the HOOF form online via the oxygen company's online portal, entering your details and the surgery details, as well as the flow rate, cylinder type and oxygen mask as given on the HOOF form in our downloads section. PLEASE NOTE: if the GP has not signed on the HOOF form to say he has completed the risk management form, the oxygen supply company will reject the HOOF form.

Once the HOOF is accepted and received, the oxygen supplier then contacts you direct to arrange delivery. The engineer delivering it will show you how to use it and supply you with masks, as well as a spare cylinder upon request. Some GPs may say they can't prescribe the oxygen and that it has to be prescribed by a secondary clinician [i.e. a consultant]. This is not so, as it is specifically laid down in the Home Oxygen Assessment Service (HOAS) specification that GPs can prescribe oxygen for CH sufferers for pain relief. There is a copy of the HOAS specification in every doctors' surgery. There is also a new type of oxygen therapy, called ultra high flow oxygen, delivered via a device known as a demand valve, similar to the device used for entinox in childbirth and for severe pain. The demand valve HOOF form for that is also available in the downloads section of the website and is also part completed for a CH sufferer. Again, the HOC and the IHORM forms have to be completed by the GP and indicated on the HOOF form and again, the GP will need to submit the form via the online portal. PLEASE NOTE that at present demand valve oxygen therapy is only available in England and Wales. Call our advice line to check if it is available in your area of England.

In Scotland oxygen can only be prescribed by a secondary clinician, i.e. a consultant, so it is more important than ever that you seek a referral to a headache specialist.

In Northern Ireland, your GP can prescribe oxygen for you on the Health & Social Care Part A Home Oxygen Order Form. But this is only a temporary measure, you will need to be assessed by a consultant who will complete the Part B form for permanent oxygen. Waiting times for HCA

appointments to see headache neurologists are around 18 months or so, and you may want to consider seeking referral to a private headache consultant instead.

The other category of drugs is the preventive drugs. The first line preventive for CH as listed in the British National Formulary [BNF] the GPs prescribing bible, is verapamil, one of a group of drugs known as calcium channel blockers. Before starting on verapamil you need to have an ECG and then further ECG's every two weeks before increasing the dosage. It can take time to build to a level where it starts to work and there are some side effects such as constipation, severe tiredness and swelling of the hands and feet. There are other preventive drugs for CH, but your neurologist will usually try the verapamil first and then work through the other drugs if you have no success with the verapamil. All preventive drugs are only taken while you are in cycle.

So hopefully you now have some means to deal with the pain of CH, but we would still suggest that you ask for referral to a neurologist who specialises in headache disorders. There are many different specialities in neurology, so it is important to specify a consultant in headache disorders. There are not many in the UK, but a quick call to the adviceline, or an e-mail to [adviceline@ouchuk.org](mailto:adviceline@ouchuk.org) will let you know who the nearest one is to you. In England, under the NHS 'Choose and Book – Choice at Referral' scheme, you can ask to be seen by a consultant of your choice, even if they are outside your Clinical Commissioning Group [CCG] area. Once you have a confirmed diagnosis from a consultant neurologist and a treatment plan outlined, it will be difficult for your GP to wriggle out of prescribing for you – some sufferers have been refused the injections and/or the oxygen on grounds of cost. Be firm but persistent in asking for what you want. A consultant will also see you at regular intervals (you do not have to be in cycle at initial consultation) to monitor your condition and see how you react to preventive medication etc.

If, despite all the foregoing information, your GP still refuses to prescribe or refer you, then you can refer him/her to the BNF, section 4.7.4.3 on cluster headache and also the NICE [National Institute for Health and Clinical Excellence] guidelines on headache disorders, sections 1.3.26 -30 deal with CH. If your GP is still refusing to prescribe or refer you, then the first step is to complain to the practice manager at your surgery and if that complaint is not dealt with to your satisfaction, then you can take your complaint to the prescriptions manager at your local CCG [they are listed in the phone book or of course you can Google them].

It's quite a struggle getting used to dealing with cluster headache and the effects it has both on you and your family. To help your family understand there is a section of our member's forum called 'Supporters of Sufferers' which they can take part in and we have a [document which you can download](#) in our Handouts for Friends and Family section called '**Pain so Severe**', which gives a description of CH and what life is like for a sufferer, all written in layman's terms. You will also find a [glossary](#) of some of the commonly used medical terms and written shorthand terms that we use when speaking about cluster headache, eg: ECH – episodic cluster headache; QS – Queen Square, the address of the National Hospital for Neurology and Neurosurgery in London. Have a good

read of the [treatments section](#) on the main OUCH website. Copies of the treatment regimes can be obtained by e-mail to [info@ouchuk.org](mailto:info@ouchuk.org) or [adviceline@ouchuk.org](mailto:adviceline@ouchuk.org). We also have a very lively Facebook group, you can come join us here: <https://www.facebook.com/groups/OUCHUK/>.

Cluster headache impacts on all aspects of a sufferer's life and the unpredictable nature of CH, means that many sufferers have lost their jobs, or at least had to change jobs because of their cluster headaches. We would suggest you contact Benefits and Employment, or Disability Rights UK. You can also contact The Brain Charity, a registered charity which supports sufferers of all neurological diseases and can advise on employment, benefits, retraining etc. OUCH has strong links with The Brain Charity and you can e-mail them <https://www.thebraincharity.org.uk/>

Cluster headache is a recognised disability and even episodic sufferers can lodge a claim for PIP [personal independence payments]. Again, [The Brain Charity](#) can help and OUCH has some advice notes under the [Downloads section](#) of our website.

**The important thing to remember is, now that you have found this website you know you are not alone suffering this disease. There is the helpline, 01646 651979, or you can e-mail on [adviceline@ouchuk.org](mailto:adviceline@ouchuk.org) for further advice and help.**