



Organisation for the Understanding of Cluster Headache

New to CH?

Well you're probably still getting your head round the fact you have a pretty nasty neurological disease that you've probably never heard of before. So what do you do now?

Firstly, you need to know what cluster headache is.

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 experience at least one 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
- Extreme restlessness/rocking/pacing up and down

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 years, but they will return. In chronic CH, the attacks occur on a daily basis with a painfree remission of less than four weeks in any twelve month period. Some chronic sufferers

experience attacks for years with no remission.

In most episodic sufferers the headaches start at the same time of year and 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. With all sufferers, attacks can occur within an hour or so 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? First and foremost, you need two things, correct prescribing 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 diagnosed yourself after doing research on your symptoms and taking our 'What kind of headache do I have?' test, you should ask your GP for an urgent referral to a headache specialist neurologist.

The first line abortive for cluster headache is subcutaneous sumatriptan [injectible sumatriptan] known as Imigran injections – or the generic Sun injection version – along with 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 and even if they were strong enough, take far too long to work. The injections will kill an attack in about 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.

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. Take it to your GP and they can then fill in your details and the surgery details and the surgery then faxes off the form to the oxygen supplier. 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. Some GPs may say they can't prescribe the oxygen, 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 Therapy Service (HOTS) specification that GPs can prescribe oxygen for CH sufferers for pain relief. There is a copy of the HOTS specification in every doctors' surgery.

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

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 helpline, or an e-mail to helpline@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 or helpline@ouchuk.org. We also have a very lively Facebook page.

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. If you have difficulties with employers, then we suggest you contact Neurosupport – Neurosupport is a registered charity which supports sufferers of all neurological diseases and can advise on employment, benefits, retraining etc. OUCH has strong links with Neurosupport and you can e-mail them via their website <http://www.neurosupport.org.uk/>.

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

The important thing to remember is, if you have found this website then you know you are not alone suffering this disease. There is the helpline, 01646 651979, or you can e-mail on helpline@ouchuk.org for further advice and help.