OUCH UK™
Organisation for the Understanding of Cluster Headache

OXYGEN THERAPY IN CLUSTER HEADACHE

Cluster headache is the only non respiratory/cardiac condition for which oxygen is prescribed under the NHS.

Cluster headache is a rare and excruciatingly painful neurological condition causing 1 to 6 attacks per 24 hours, of excruciating pain on one side of the head, lasting anything from 30 minutes to 3 hours [or more], accompanied by the following cranial autonomic symptoms:

- Reddening and watering of the eye.
- A blocked or runny nose.
- Droopy eyelid
- Constriction of the pupil
- Yawning
- Extreme restlessness.

The disease takes two forms, episodic – where attacks occur for a period of weeks or months and then stop as suddenly as they started [but they will come back] – and chronic where the sufferer experiences daily attacks for a period of over a year with a painfree remission of only four weeks or less within that year. Some chronic sufferers have endured up to 25 years with little or no painfree remission. It is a lifelong condition and at present is incurable.

Episodic bouts typically occur in late March, late October and the end of the year, all times when the seasons change and of course we change clocks.

The cause of cluster headache has been shown to be an abnormality of the hypothalamus, a small organ at the base of the brain, but which has a very important role in the human body as it controls the autonomic system, all the things we don't think about, such as hunger, thirst, tiredness, sex drive, bowel function etc. It also reacts to the circadian rhythms of nature. A series of PET imaging of the brains of sufferers, who had had attacks induced, showed the same area of the posterior hypothalamus increased activity on the same side of the brain as the attacks occur and this was present in every image. This activity sends a false signal that the brain is short of oxygen [hence yawning as a pre-monitory symptom] and the blood vessels start to expand in the search for more oxygen, causing extreme pain.

The usual treatments recommended by the BNF, the NICE GPs headache pathways, and the BASH guidelines are subcutaneous sumatriptan or nasal sprays, and standard high flow oxygen. The subcutaneous sumatriptan works fastest and best within about 8 to 10 minutes but can only be used twice in 24 hours; standard high flow oxygen can be used as many times as needed provided there are no pre-existing chest conditions that prevent its use. Using oxygen alone, an attack can be aborted in about 20 to 30 minutes.

In 2016 the NHS included demand valve oxygen therapy for use in cluster headache. The oxygen is delivered via a mouthpiece identical to that used in entonox [as in childbirth] and it delivers ultra high flow oxygen. This particular form of oxygen therapy is more cost efficient because of the way

the demand valve works – it shuts off on exhalation and is not blasting out all the time – a cylinder lasts far longer than with the standard high flow non-rebreather mask and for the same reason is much safer than the standard high flow oxygen which is absorbed by skin and clothing as it is constantly flowing and presents a much higher accelerant risk. There is also a very low suffocation risk if the patient falls asleep and the cylinder runs out, as the mouthpiece just falls away and shuts off automatically.

For a cluster headache patient, oxygen is vital. Without oxygen, sufferers are faced with at least two to four attacks a day [or more] with no pain relief, broken sleep, confined to home because they dare not go out; they can lose their jobs, their homes, their family and friends, have poor quality of life and depression is common; having to face the thought of a life of daily attacks of pain that are off the scale is far from easy. Not for nothing is the condition known as 'suicide headache.' Portable oxygen means that sufferers can get out and about, could keep their jobs, do all things that non-sufferers don't have to think about and improve their quality of life.

Currently the difficulties for cluster headache sufferers who are undiagnosed and awaiting an appointment with a headache neurologist, are that GPs are reluctant to prescribe as described above and assume that the patient has a migrainous condition, and prescribe things like paracetamol, ibuprofen, anti-depressants, co-codamol and codeine – none of which will touch cluster headache pain. On our website, we have a questionnaire 'Do I have Cluster Headache?' which guides the patient towards the type of headache they might have. We also have a document called 'Cluster Headache Basics', which describes the condition, tells the sufferer what medications they can ask for, has links to the Home Oxygen Order Form for a CH patient, and links to the BNF, NICE GP headache pathways and other items that the patient could show the GP.

With both BNF-suggested treatments, at least the patient can have some relief while waiting to see a consultant. The night attacks can be worse, as they have reached a high pain level by the time the patient wakes and are harder to get rid of, so the double whammy of the injection and the high flow oxygen have a good chance of getting rid of the attack within a reasonable timeframe. Both treatments work best as soon as the patient realises they have an attack starting, to delay in case it goes away – well it just does not happen.

For further details and more in depth information on prescribing and usage of oxygen please refer to **Cohen, Burns, Goadsby, [2009]** https://pubmed.ncbi.nlm.nih.gov/19996400/ with regard to standard high flow oxygen therapy in cluster headache. OUCH [UK] also did an anecdotal study of demand valve [ultra-highflow oxygen therapy] in 2014. The success rate with demand valve was higher than the already good results of the 2009, Cohen, Burns and Goadsby study.

For further information on the condition itself, please visit our website www.ouchuk.org, And:

Wei, Khalil, & Goadsby [2019]https://pn.bmj.com/content/19/6/521

Villar-Martinez, Puledda, Goadsby [2020]
https://link.springer.com/article/10.1007/s11940-020-00655-z