Advice on Oxygen Treatment for Cluster Headache in Adults

London Clinical Oxygen Network

Information for boroughs, respiratory clinicians and HOSAR teams

Cluster headache is the only indication for oxygen therapy in the absence of hypoxia. High flow oxygen is very effective in some patients in relieving symptoms of an acute cluster headache (CH) quickly and safely. The evidence base is clear, and the use widely accepted in the medical (1) and patient communities (www.ouchuk.org). In the majority of these patients, the headaches occur in clusters (bouts) with daily attacks for several weeks. Cluster headache bouts alternate with remission periods, when patients are pain free. During the remission phase oxygen may be unused but carried just in case patients have sudden recurrence of symptoms.

Patients are often started on a supply by a neurologist via a GP and thereafter self-manage their supplies; this can lead to problems with under supply, misuse and frustration. The range of oxygen equipment which can be prescribed by a non-specialist is limited and specialist assessment is needed to get this right. This guidance has been developed by the London Clinical Oxygen Network in collaboration with Kings College London, and the Organisation for Understanding Cluster Headache- UK (OUCH-UK) to offer some insight into CH and the type of support required.

Oxygen Prescription in Cluster Headache

CH oxygen supplies should be in one of 2 formats: a static supply or, for those patients who are mobile, a static supply with some ambulatory cylinders (and a carry bag).

1. Static:
   - 12-15 L/min flow as required
   - x1 static back-up cylinder
   - x1 Non rebreathe high concentration mask fitted with a reservoir
   - or

2. Static and Ambulatory
   - 12-15 L/min flow as required
   - x1 static back-up cylinder
   - X4 Standard ambulatory cylinders
   - X1 Non rebreathe high concentration mask fitted with a reservoir

Example CH Home Oxygen Order Forms are available.

Oxygen supplies for patients with CH no longer cost vast sums. The equipment rental is relatively cheap; deliveries are the expensive element and therefore costs related to an infrequent oxygen user should be minimal (on-going costs of option 1 above may be <£80 p.a).

Useful information to offer patients starting oxygen for CH

The general guidance for patients is that **if there is no relief from oxygen therapy in within 15 minutes they should cease using it and move to an alternative for that attack.** If the oxygen has not worked, the patient should turn off the oxygen and try again with the next attack. If the attack is successfully aborted, the patient should be advised to stay on the oxygen for 5-10 minutes after the pain has gone to “mop up” the attack and prevent possible rebound, which is described by some patients. This means that even a small cylinder may support 2-3 attacks.
Patients need to know that if they do not find oxygen helpful, or they do not want to continue to use it, they must let a health professional know so that the HOOF can be cancelled.

**HOSAR assessment for CH patients**

Patients newly prescribed oxygen for cluster headache should have a **specialist HOSAR assessment** to offer individualised patient and carer education about oxygen treatment, a comprehensive risk assessment and carbon monoxide monitoring ([Responsible Oxygen Prescribing Messages](https://www.networks.nhs.uk/nhs-networks/london-lungs)). It is estimated that around 60% of CH patients smoke. 1 in 4 oxygen related domestic fires results in death and 1 in 3 results in serious injury therefore patient education and risk assessment are crucial aspects of safe home oxygen prescription. Patients should be informed of their responsibility to use oxygen safely, including abstinence from smoking while on oxygen and of the reasons for this. Time should be allowed to check patients’ understanding of this information. The frequency of CH attacks is not related to smoking; however brief verbal advice about the health benefits of quitting smoking should be given at every contact and referral to their local smoking cessation service should be offered where appropriate ([for information and resources see](http://www.londonsenate.nhs.uk/helping-smokers-quit/)).

Consideration should also be given to whether the patient may have a long term condition predisposing to hypoventilation (eg COPD, obesity hypoventilation or kyphoscoliosis) which could put them at risk if they are prescribed uncontrolled high flow home oxygen prescription without specialist assessment.

Once on oxygen CH patients should be assessed to see if their symptoms have responded to therapy; those that do not respond are unlikely to ever benefit and a removal should be arranged. Let the patient’s GP and neurologist know if this is the case.

CH patients on oxygen may not need ongoing HOSAR review if their use is low and appears controlled. Those requiring frequent refill visits >2 weekly should be reviewed to check that their equipment is meeting their need. Some CH patients go for so long without a cluster bout that they offer to return the equipment, only to need stocks at short notice. This then causes a problem with the need for a HOOF B. In these cases it may be helpful for their GP to keep a model copy of their cluster headache HOOF so that it can be sent off without delay.

CH patients with frequent refills and urgent orders also require a review of their equipment, usage and needs. Urgent call outs are inconvenient, costly and far exceed the cost of holding a few more cylinders. If patients have room and risk assessment allows, consider more stocks to the limit of 8.

Clinical concerns should be addressed to their neurologist and/or GP in the first instance.

**Background Information: Cluster Headaches**

**Purpose**

To outline the right approach to the needs of London Cluster Headache (CH) patients in the light of:

- the terms of the 2012 home oxygen supply (HOS) contract which requires the prescriber to select equipment rather than leaving equipment selection to the gas supplier
- restriction of GP ordering to a temporary or emergency supply (HOOF A) which does not include ambulatory devices
- uncertainty by those trained to be HOOF B prescribers on the use of oxygen in CH
- problems in GP ordering at the request of neurologists and the limited ability of specialist headache clinics in London to follow up patients (with few clinical nurse specialists available to support patients)
- advice from the Cluster headache support group (OUCH-UK)
Overview

Cluster Headache is a rare condition with a prevalence of approximately 1:1000 adults (1). The condition usually starts in early adulthood but can occur through the whole age range. It may spontaneously improve with age. The diagnosis is often delayed, typically 2-3yrs. Confusion with migraine is common with the accurate diagnosis often being made after specialist referral. Attacks last between 15mins and 3 hours and occur at a frequency ranging from one every alternate day to up to eight daily. The headache is excruciating, typically confined to one half of the head and associated with cranial autonomic features such as lacrimation, conjunctival injection, eyelid oedema, nasal congestion, rhinorrhoea and facial redness. Unlike migraine, suffers are restless and agitated during attacks (2). The majority of the attacks occur spontaneously though alcohol, the smell of volatile substances, heavy exercise and raised ambient temperature can all trigger attacks. During attacks individuals may be unable to undertake normal activities of daily living. Suicide is a recognised concern (3).

CH patients fall into 2 groups (2):

1. Episodic CH affects 80-90%: diagnosed when individuals experience recurrent bouts with a duration of more than a week and separated by remissions lasting more than a month. Most patients have one or two annual cluster periods, each lasting between one and three months. Often the bouts occur in the same month of the year.

2. Chronic CH affects 10-20%: diagnosed when either no remission occurs within one year or the remissions last less than one month.

Treatment

In clinical trials, 76% of affected people obtain benefit during an attack from oxygen therapy (4). Unfortunately the oxygen concentrators available through the NHS contract do not provide sufficient oxygen enrichment or high enough flow rate to be effective. Some CH patients may opt to purchase high flow concentrators but, in most, static large capacity oxygen cylinders will be required to treat home attacks and portable cylinders when away from home. Non-rebreathe high-concentration masks with a reservoir (as used by ambulances and in emergency resuscitation areas) should be used at a flow rate of 12-15 L/min. The value of the reservoir bag is to reduce entraining of air at the mask and to conserve oxygen. The flow rate should be set so as to avoid collapse of the bag during inspiration.

The response to high concentration oxygen occurs within 15 minutes. If there is an inadequate response after 15 minutes the advice is to turn the oxygen supply off. For those sufferers who respond to oxygen, the advice is to continue oxygen treatment for 10 minutes after the headache has abated otherwise they may have a rebound headache. There are no characteristics that predict responsiveness to oxygen. Non-responders do not generally become responders so there is no value in such people continuing to be provided with oxygen (and therefore discontinuing the HOOF order is required). It could be argued that in episodic CH the equipment could be returned between clusters but this requires that repeat prescribing at the start of a further cluster is timely and easily organised.

Subcutaneous sumatriptan is also very effective and is often preferred, for efficacy and to a lesser extent convenience reasons. It is licensed for use twice in 24 hrs. As attacks may occur more frequently, many with CH request a domiciliary oxygen supply, using the subcutaneous injection when out of the home. The cost of an injection is £20 which may be a factor limiting prescribing in primary care. Nasal triptans have evidence for their effect, notably zolmitriptan (5) and sumatriptan (6), and can also be used but may work more slowly than subcutaneous sumatriptan and oxygen.

With regard to preventive treatment, verapamil reduces the frequency of cluster headache attacks but specialist advice is recommended (7).
Oxygen prescriptions

In England most home oxygen prescribing is carried out by home oxygen assessment and review services (HOSARs) to which neurologists and GPs are able to refer. The number of CH patients in Greater London is estimated to be 8000, on the basis that the population of Greater London is 8 million and the prevalence of CH is 1 per 1000. Home oxygen in cluster headache seems to be considerably under-utilised in Greater London.

Risks with high flow oxygen

Oxygen is a medicine which should only be prescribed and reviewed by staff trained in oxygen prescription and use (Responsible Oxygen Prescribing Messages: https://www.networks.nhs.uk/nhs-networks/london-lungs). Every patient who has been newly prescribed home oxygen should have a specialist oxygen assessment to offer individualised patient and carer education about oxygen treatment, a comprehensive risk assessment and carbon monoxide monitoring. This can be done by their local specialist HOSAR team who should be made aware of local CH patients on oxygen.

It is estimated that around 60% of CH patients smoke. 1 in 4 oxygen related domestic fires results in death and 1 in 3 results in serious injury therefore patient education and risk assessment are crucial aspects of safe home oxygen prescription. Patients should be informed of their responsibility to use oxygen safely, including abstinence from smoking while on oxygen and of the reasons for this. Time should be allowed to check patients’ understanding of this information. The frequency of CH attacks is not related to smoking; however brief verbal advice about the health benefits of quitting smoking should be given at every contact and referral to their local smoking cessation service should be offered where appropriate.

Consideration should also be given to whether a patient may have a condition predisposing to hypoventilation (eg COPD, obesity hypoventilation or kyphoscoliosis) which could require clinical assessment before uncontrolled high flow home oxygen prescription.

Pathway for prescribing oxygen for cluster headache patients

The NICE clinical guideline for Headaches (CG150) provides an outline for the assessment, diagnosis and treatment of cluster headache (3). The NICE guideline recommends the following pathway for managing these patients:

1. Evaluate people who present with headaches for red flags that raise the possibility of symptomatic (secondary) causes for headaches and consider the need for further investigations and/or referral.

2. For people with primary headaches (i.e. in whom secondary causes have been excluded) diagnose cluster headache according to the headache features in the attached table 1

3. Discuss the need for neuroimaging for people with a first bout of cluster headache with a GP with a special interest in headache or a neurologist.

4. Offer oxygen for the acute treatment of cluster headache.
Table 1. Diagnosis of cluster headache compared with tension-type headache and migraine

<table>
<thead>
<tr>
<th>Headache feature</th>
<th>Cluster headache</th>
<th>Tension-type headache</th>
<th>Migraine (with or without aura)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain location†</td>
<td>Unilateral (around the eye, above the eye and along the side of the head/farce)</td>
<td>Bilateral</td>
<td>Unilateral or bilateral</td>
</tr>
<tr>
<td>Pain quality</td>
<td>Variable (can be sharp, boring, burning, throbbing or tightening)</td>
<td>Pressing/tightening (non-pulsating)</td>
<td>Pulsating (throbbing or banging in young people aged 12-17yrs)</td>
</tr>
<tr>
<td>Pain intensity</td>
<td>Severe or very severe</td>
<td>Mild or moderate</td>
<td>Moderate or severe</td>
</tr>
<tr>
<td>Effect on activities</td>
<td>Restlessness or agitation</td>
<td>Not aggravated by routine activities of daily living</td>
<td>Aggravated by, or causes avoidance of, routine activities of daily living</td>
</tr>
<tr>
<td>Other symptoms</td>
<td>On the same side as the headache:</td>
<td>None</td>
<td>Unusual sensitivity to light and/or sound or nausea and/or vomiting Aura²</td>
</tr>
<tr>
<td></td>
<td>• red and/or watery eye</td>
<td></td>
<td>Symptoms can occur with or without headache and:</td>
</tr>
<tr>
<td></td>
<td>• nasal congestion and/or runny nose</td>
<td></td>
<td>• are fully reversible</td>
</tr>
<tr>
<td></td>
<td>• swollen eyelid</td>
<td></td>
<td>• develop over at least 5 minutes</td>
</tr>
<tr>
<td></td>
<td>• forehead and facial sweating</td>
<td></td>
<td>• last 5–60 minutes.</td>
</tr>
<tr>
<td></td>
<td>• constricted pupil and/or drooping eyelid</td>
<td></td>
<td>Typical aura symptoms include visual symptoms such as flickering lights, spots or lines and/or partial loss of vision; sensory symptoms such as numbness and/or pins and needles; and/or speech disturbance.</td>
</tr>
<tr>
<td>Duration of headache</td>
<td>15–180 minutes</td>
<td>30 minutes–continuous</td>
<td>4–72 hours in adults</td>
</tr>
<tr>
<td>Frequency of headache</td>
<td>1 every other day to 8 per day², with remission⁴ &gt; 1 month</td>
<td>1 every other day to 8 per day², with a continuous remission⁴ &lt;1 month in a 12-month period</td>
<td>4–72 hours in young people aged 12–17 years</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>Episodic cluster headache</td>
<td>Chronic cluster headache</td>
<td>Episodic tension-type headache</td>
</tr>
</tbody>
</table>

† Headache pain can be felt in the head, face or neck.
² See recommendations 1.2.2, 1.2.3 and 1.2.4 for further information on diagnosis of migraine with aura.
³ The frequency of recurrent headaches during a cluster headache bout.
⁴ The pain-free period between cluster headache bouts.
⁵ Chronic migraine and chronic tension-type headache commonly overlap. If there are any features of migraine, diagnose chronic migraine.
⁶ NICE has developed technology appraisal guidance on Botulinum toxin type A for the prevention of headaches in adults with chronic migraine (headaches on at least 15 days per month of which at least 8 days are with migraine).
References


Irem Patel and Debbie Roots
London Clinical Oxygen Network
September 2016