

## **Information for GPs and Neurologists: Arranging Short-burst Oxygen Therapy for patients in England and Wales with Cluster Headaches**

Although rare, cluster headache is an excruciating headache that occurs in 1 - 8 attacks a day or more. High flow short-burst oxygen aborts attacks in some patients with cluster headache (100% oxygen at 12 L/min for up to 15 minutes). This is the only evidence-based use for short-burst oxygen therapy in patients who do not have hypoxaemia.

It should be offered to patients to try as soon as the diagnosis has been made so that those who find it helpful can continue to use it (and those that don't stop using it). Cluster headache attacks mostly occur at unpredictable intervals; a patient can be at work, out shopping, walking the dog and within a few minutes be in excruciating pain. For patients who find that oxygen aborts their attacks, it needs to be provided both at home as free-standing cylinders and may be needed in a form that can be used when out and about ie ambulatory cylinders.

All patients starting oxygen need education and information so that they understand how to use oxygen safely and effectively.

All home oxygen cylinders are provided by one of a number of regional contractors according to a daily tariff irrespective of how many cylinders are used.

Oxygen can be ordered by any health professional provided the order forms are completed appropriately. It should therefore be ordered when the diagnosis of cluster headaches is made by the doctor, either GP or neurologist, seeing the patient.

### **To order oxygen:**

1. Complete in full a Home Oxygen Order Form (HOOF), available from

<http://www.pcc.nhs.uk/home-oxygen-order-form>

- Record clinical code 20 (Cluster headache) in Section 1.17 and state 'cluster headache sufferer' in clinical information
- Complete Section 7 Short Burst Oxygen Therapy:
  - 7.1 flow 12 Litres/minute
  - 7.2 duration 15 Minutes/day. Patients should be reassured they can use more than this but use is estimated as an average over a prolonged period.
  - 7.3 Services. Mask 100% oxygen.
- If needed complete Section 6 Ambulatory Service.
  - 6.1 12 Litres/minute
  - 6.2 < 1 Hour/day. Patients should be reassured they can use more than this but use is estimated as an average over a prolonged period
  - 6.3 Services. Mask 100% oxygen
- Delivery details section 8. Tick Standard.

2. Ensure the patient has completed a Home Oxygen Consent Form (HOCF) available from

<http://www.pcc.nhs.uk/uploads/HOS/December%20Uploads/DH%20APPROVED%20HOCF.pdf>. Home oxygen will only be provided if this form has been completed. The HOCF should be filed in the patient's notes.

3. Fax the HOOF to the appropriate contractor listed on Page 2, Section 8 of the HOOF so that short-burst oxygen can be organised.

### **Useful information to offer to patients starting oxygen:**

Patients should be advised to use oxygen for no more than 15-20 minutes at a time. If the oxygen has not worked by 20 minutes, 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. When starting oxygen patients may find it helpful to keep a diary of attacks and response to oxygen. 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 the health professional who ordered the oxygen know so that the HOOF can be cancelled by faxing the supplier.

## Equipment details

### Mask interface

Non-rebreathe mask with a reservoir bag used with the two holes covered (historical not evidence based)

### Free-standing cylinders

Patients need two free-standing 2000 L cylinders so they can immediately switch to a second cylinder and order a replacement for an empty one ensuring continuity of supply and treatment. Each cylinder can treat between 8-30 attacks depending on the speed of response.

### Ambulatory oxygen

Ambulatory cylinders enable oxygen use flexibly outside the home (carried in cars and in storage backpacks). However, as they are much smaller cylinders (typically 400 L) they only contain enough oxygen to treat a small number of attacks.

### Liquid oxygen therapy (LOX)

A small number of patients with severe chronic cluster headache (3-6 attacks daily throughout the year) who find oxygen aborts their headaches may benefit from liquid oxygen because of their high total hours of high flow oxygen needed. One LOX cylinder can provide 1 hour of treatment.

### Other sources of education and information:

- Hospital neurology team
- Hospital respiratory team (provide education and information to a large group of respiratory patients using oxygen).
- OUCH (Organisation for the Understanding of Cluster Headache) <http://www.ouchuk.org>; UK Charity whose aim is to raise awareness of cluster headache with the medical profession and the public and to offer support and guidance to sufferers and their families.