

# FACT SHEET

## Cluster Headache

### What is cluster headache?

*"They often wake me in the middle of the night, a couple of hours after I've gone to bed. They build up in a matter of seconds and the pain is just excruciating. It's only in my right eye, like a red hot poker. I don't know where to put myself. I have to do something to distract from the pain. Sometimes I pace up and down the room holding my head, or just sit in the chair and rock."*

Cluster Headache describes attacks of severe one-sided pain in the head. Each attack develops suddenly, usually without any warning. The headaches occur in groups, or "clusters" of 1-8 attacks daily, generally occurring at the same times and most often with the first one waking sufferers within an hour or so of falling asleep.

### Who gets cluster headache?

Cluster Headache is uncommon but affects at least 2-4 in 1000 people, possibly more. Men are more often affected than women. The first cluster typically develops between the ages of 20- 40 years, but it can start at any age and there are cases of very small children and young people in their teens.

### What are the different types of cluster headache?

The more common type of Cluster Headache is Episodic. This is the name given to daily attacks that occur in clusters lasting for an average of 6-12

weeks, although clusters can last anything from two or three weeks up to five or six months. Clusters usually come around the same time each year, with some sufferers having two or three bouts every year and others having gaps of a few years.

About 1 in 10 cases of cluster headache are chronic, without an obvious pattern and with limited respite.

### What are the symptoms of cluster headache?

Cluster Headache is extremely painful – so severe that it has been called 'suicide' headache. The pain is one-sided and almost invariably occurs on the same side, beginning behind one eye and rapidly worsening.

The pain is often described as searing, knifelike or boring, especially in and around the eye. The pain reaches full force rapidly, within 5-10 minutes of onset, and each untreated attack typically lasts around an hour but can be anything between 15 minutes and 3 hours.

In contrast to migraine, when most people want to lie down during an attack and keep as still as possible, the pain of Cluster Headache is so intense that sufferers are unable to remain still and they will pace around or rock violently backwards and forwards. On the affected side only, the eye becomes reddens and waters. The nostril feels blocked up or will run. The other side of the face is completely unaffected.

**the City of London Migraine Clinic**

22 Charterhouse Square · London EC1M 6DX · Tel: 020 7251 3322 · Fax: 020 7490 2183

Website: [www.migraineclinic.org.uk](http://www.migraineclinic.org.uk)

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# FACT SHEET

## Cluster Headache

### Do I need any tests?

There are no tests to confirm the diagnosis, which is based on the description of the headaches and the lack of any abnormal findings on examination. If there is any uncertainty about the diagnosis, tests may be done to rule out other causes of headaches.

### What causes cluster headache?

Despite intense medical interest in researching the causes and process of attacks of Cluster Headache, the cause remains unknown. Much interest centres on the timing of attacks, which appears to link to circadian rhythms, i.e the biological clock. Many sufferers report that their clusters are more likely to start around the time of the spring and winter solstice. Recent research has highlighted changes in part of the brain known as the hypothalamus, the area that controls the body clock.

### What are triggers?

Alcohol often triggers an attack within 20 minutes during an episode, but not at other times. Sufferers often are or have been heavy smokers, or have lived with heavy smokers. The reasons for this association are not clear and stopping smoking rarely has any effect on the condition. Other recognised triggers include exercise and elevated environmental temperatures.

### Will it get better?

Fortunately for many sufferers, particularly those with chronic cluster headache, cluster often improves in later life.

### What can I do to help myself?

Ordinary painkillers do not work. These are just not strong enough for the pain of Cluster Headache and take too long to work. For effective treatment, you will need to seek medical advice as specific drugs are indicated that are not available without prescription.

### Keep a diary

Diary cards can be used to record a great deal of relevant information about your headaches, particularly how often you get them, how long they last and what your symptoms are. They are also valuable in assisting diagnosis, assessing trigger factors and assessing the effectiveness of treatments.

### What treatment can I take?

Drug treatment is always necessary. The most effective treatments to treat the symptoms of an attack (acute medications) are oxygen and sumatriptan. Some medicines are taken every day for the duration of a cluster episode to prevent headaches developing (preventive medications). Verapamil is the usual first choice. In most cases, both preventive and acute treatments are necessary to achieve adequate control.



# FACT SHEET

## Cluster Headache

### Acute medications

(to treat symptoms when they occur)

**You need to treat the attack as early as possible since treatment is less effective once attack reaches its peak.**

**Subcutaneous sumatriptan is the only drug licensed\* for the acute treatment of Cluster Headaches.**

**Oxygen:** 100% oxygen delivered at 7-12 litres per minute through a non-rebreathing mask for 10-20 minutes. You should sit leaning forward with the mask firmly over your face ensuring it is a tight fit and there are no leaks.

To obtain oxygen as an initial emergency order, your GP can send a Home Oxygen Order Form (HOOF) to the oxygen supplier who has the contract for your region. A part completed sample form is included in this fact sheet. A second non-urgent HOOF should be completed at the same time for your ongoing supply.

The first time you get oxygen, you will also need to complete a Home Oxygen Consent Form (HOCF). This is not providing consent to oxygen treatment but giving consent for the transfer of your personal details (eg. Name, address etc) to the Home Oxygen Service Supplier.

All cylinders (a 1,360 litre size cylinder and a 460 litre portable size) will come complete with their own integral high regulator of up to 15 litres per minute. The oxygen supplier will also provide non-rebreathing masks.

The supplier should deliver the oxygen cylinders directly to you within four hours. If you live in Scotland, your GP will write a prescription for oxygen and you will need to obtain a high flow regulator.

**Sumatriptan:** 1 x 6 mg subcutaneous injection at the onset of the attack or 1 x 20mg intra-nasal spray administered into one nostril. You can use a maximum of 2 doses in 24 hours, with a minimum of at least 2 hours between doses.

**Octreotide:** is indicated for sufferers who do not respond to triptans or are intolerant of them. 100 mcg is injected subcutaneously.

**Lignocaine:** a 4% solution of this anaesthetic drug can be used as nose drops or a spray for acute treatment of an attack. The usual dose is to use 15 drops in the nostril of the affected side at the onset of the headache. This can be repeated after 15 minutes. Side effects include light-headedness and feeling agitated.

**Alternative therapies:** anecdotal reports have identified hot / cold therapies and biofeedback have helped to lessen the pain and shorten attacks but are not an effective replacement for medication.

### Preventative medications

(taken to prevent attacks during a cluster)

**Methysergide is the only effective drug licensed\* for prevention of Cluster Headache**

**Verapamil:** This is most often prescribed as a first-line choice, building up the dose over several days until an effective dose is reached. Although many sufferers respond to doses 120 mg 3-4 times daily, higher doses, up to 960mg daily in divided doses may be necessary. Since high doses can affect the heart, electrocardiograms (ECG) should be performed before verapamil is started and repeated as the dose is increased. The effective dose should be continued for the usual duration of the cluster, then gradually reduced over 1-2 weeks. If attacks recur, the dose can be increased again and reduced at 2-week intervals. Verapamil is usually well tolerated although constipation (which may be severe) and flushing are common side-effects. Good dental care is important as gum bleeding from gingival hyperplasia can occur.

**Lithium:** This is an option if verapamil is not effective. The kidneys, heart and thyroid are checked before lithium is started and while it is being taken. The usual dose is 300-600mg twice daily but higher doses are sometimes necessary. Blood tests are required to ensure an adequate level of the substance in the bloodstream. Certain drugs, including non-

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## Cluster Headache

steroidal anti-inflammatory drugs (NSAIDs), diuretics and carbamazepine should be avoided when taking lithium. This is because they can increase the blood levels of lithium causing toxic side effects.

**Ergotamine:** Half to one Cafegot® suppository (1-2 mg) 1-4 hours before expected attack, e.g. for use at bedtime for night-time attacks, can be useful for short bouts of episodic cluster headache.

**Steroids:** Prednisolone enteric-coated 60-100mg daily in single or divided doses is taken for 5 days, before reducing by 10mg every 2-3 days. Steroids can be used for short-term prevention until other preventives take effect. Gastric irritation is the most common problem. They are rarely used long-term as they increase bone loss and the risk of infections.

**Methysergide:** This is one of the most effective drugs available but prolonged use has been associated with kidney, lung and heart damage. 1-4 mg daily in divided doses is effective for the majority of sufferers. Occasionally, higher doses may be prescribed under close medical supervision. It should not be taken for more than 6 months at a time without a one-month break. Initial side-effects of nausea, abdominal discomfort and leg cramps usually settle with continued use.

**Other drugs:** These include valproic acid, sodium valproate, topiramate, naratriptan and eletriptan which have been tested but the evidence for their effectiveness in Cluster Headache is inconclusive. Pizotifen is not effective, despite being licensed for this indication.

**Always consult your doctor before starting any treatment for Cluster Headache.**

All the above treatments (acute and preventative) are only recommended once the diagnosis has been confirmed. This is particularly important for uncommon conditions.

\* Unlicensed use of a licensed medication: the Medicines and Healthcare Products Regulatory Agency (MHRA) approve the use of medicines for specific indications. However,

these indications often do not reflect current evidence and may be unnecessarily restrictive. Hence, if there is a sufficient body of evidence to show an additional benefit for a specific drug, doctors may depart from the prescribing directions given in the data sheet of licensed medicines and prescribe them 'off-licence'.

### What if drugs don't work?

Several surgical strategies have been tried for intractable chronic cluster headache. Injections of a combination of a local anaesthetic and a steroid can be used to block the greater occipital nerve on the affected side. There are two occipital nerves, one each side of the base of the skull. Each is located just underneath the scalp, supplying feeling to the skin over half of the back of the head. Although the benefits of a greater occipital nerve block have been confirmed in placebo-controlled clinical trials, the effects may not last long and repeated treatment is less effective. Sometimes the skin around the site of the injection can thin and lose hair but serious complications are very rare.

Another approach has been to implant an electrode under the scalp, which continuously stimulates the greater occipital nerve. Although more research is needed, this option is preferable to more invasive surgical options including surgery of the trigeminal ganglion and deep brain stimulation of the hypothalamus.

These strategies are reserved for the most resistant cases as they are not without risks and cannot be guaranteed to be effective.

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### Useful Contact:

The Organisation for Understanding Cluster Headache (OUCH UK)  
Help line: 01646 651 979  
Website: [www.ouchuk.org](http://www.ouchuk.org)  
E-mail: [info@ouchuk.org](mailto:info@ouchuk.org)

This information is provided as a general guide only. If you have any queries or concerns about your headaches or medications please discuss them with your GP or your City of London Migraine Clinic Doctor.

Dr Anne MacGregor Updated Sept 2011

*We are grateful to BOC Medical for supplying the oxygen cylinders and masks at the City of London Migraine Clinic.*



**Patient agreement to sharing information**  
(as part of the supply of Oxygen by the Home Oxygen Service)



<b>Form issued by:</b>			
<b>Unit/Surgery</b>		<b>Address</b>	
<b>Contact name</b>			
<b>Tel no.</b>			
		<b>Postcode</b>	

<b>Patient</b>			
<b>Name</b>		<b>Address</b>	
<b>D.O.B.</b>			
<b>NHS number</b>			
<b>Tel/mobile no.</b>			
<b>E-mail</b>			
		<b>Postcode</b>	

My doctor or a member of my care team has explained the arrangements for supplying Oxygen at my premises, that my information will be stored in line with the Data Protection Act 1998, and I understand these arrangements, such that:

- information about my condition/condition of the patient named above\* will be transmitted to the Home Oxygen Service (HOS) Supplier to enable them to deliver the Oxygen treatment as per the Home Oxygen Order Form (HOOF),
- information will be exchanged between my hospital care team, my doctor, the home care team and such other teams as necessary related to the provision, and review, of my Oxygen treatment and safety,
- the HOS Supplier will be granted reasonable access to my premises, so that the Oxygen equipment can be installed, serviced, refilled and removed (as appropriate),
- information will also be shared with the local Fire Rescue Services team to allow them to offer safety advice at my premises and where appropriate install/deliver suitable equipment for safety, and
- information will also be shared with my electricity supplier/distributor where electrical devices have been installed.
- From time to time, I may be contacted to participate in a patient satisfaction survey/audit. *(should you wish not to participate please inform your HOS supplier)*
- I understand that I may withdraw my consent at any time (at which point my HOS equipment will be removed)

\* Delete as applicable

<b>Patient's signature</b>		<b>Date</b>	
(see note 3 where signed and witnessed on patient's behalf)			

I confirm that I have responsibility for the above-named patient.

<b>Carer's signature</b>		<b>Name</b>	
<b>Relationship to patient</b>		<b>Date</b>	

I confirm that I am the healthcare professional responsible for the care of this patient and I have completed this form on his/her behalf as s/he is unable to provide/withhold consent. The patient has been given a copy of this form.

<b>Clinician's signature</b>		<b>Date</b>	
<b>Name</b>			

## GUIDANCE NOTES

### *Who may give consent?*

1. It is presumed that anyone aged 16 or over is competent to give consent for her/himself unless the opposite is demonstrated. If a child under the age of 16 has 'sufficient understanding and intelligence to enable him or her to understand fully what is proposed', then he or she will be competent to give consent for him/herself. Young people aged 16 and 17, and legally 'competent' younger children, may therefore sign this form for themselves, but may like a parent to countersign as well.
2. If a child is unable to give consent him/herself, person(s) with parental responsibility for the child may provide information about their wishes in relation to the child. However, the final decision to disclose information lies with the healthcare professional in charge of caring for the child. Any decisions taken must be in the best interests of the child. Even where a child is able to give consent him/herself, a healthcare professional with responsibility for caring for the child should involve those with parental responsibility for the child's care, unless the child specifically asks the healthcare professional not to do so.
3. If a patient is mentally competent to give consent but is physically unable to sign a form, this form should be completed and signed by an independent witness as confirmation that the patient concerned gave consent orally or non-verbally.
4. Where an adult patient (aged 18 or over) lacks capacity to give or withhold consent, decisions must be taken by the healthcare professional in charge of the care of the patient. Decisions must be made in the best interests of the patient, taking into account any wishes that may have been previously expressed by the patient (for example, before he loss of capacity) and any views or wishes expressed by the patient's family or friends.

### *Guidance on the law on confidentiality and consent*

For a comprehensive summary, see the Department of Health publication

*Confidentiality: NHS Code of Practice* available at

[http://www.dh.gov.uk/en/Managingyourorganisation/Informationpolicy/Patientconfidentialityandcaldicottguardians/DH\\_4100550](http://www.dh.gov.uk/en/Managingyourorganisation/Informationpolicy/Patientconfidentialityandcaldicottguardians/DH_4100550)

# Home Oxygen Order Form (HOOF)

Read guidance notes before completing.



## Before you start

Use this form as a healthcare professional ordering patient oxygen for a home setting.

Make sure you complete all sections accurately and legibly to avoid rejection. Mark (X) all options that apply (leave others blank). Include contact name and telephone number to resolve queries.



## Completed the Home Oxygen Consent Form (HOCF)

By law, patient's consent is needed to transfer personal information to supplier and for supply to begin.

If no consent, order will be rejected.

## After completing this form

Keep copy in patient records.

GP: Fax to supplier and PCT/LHB.

Hospital or Clinic: Fax to supplier, patient's GP and PCT/LHB.

Supply problem: Refer patient to supplier helpline.

1 PATIENT'S DETAILS		
1.1 Title <input type="text"/>	1.10 Carer's name <input type="text"/>	<b>Clinical details</b> 1.17 Clinical code <input type="text" value="20"/> 1.18 <input type="checkbox"/> Paediatric order 1.19 <input type="checkbox"/> On NIV/CPAP 1.20 <input type="checkbox"/> Tracheostomy 1.21 <b>Important details</b> Add additional patient information helpful to supplier (disability, frail, language needs) <input style="width: 100%; height: 100%;" type="text"/>
1.2 Surname <input type="text"/>	1.11 Carer's tel no. <input type="text"/>	
1.3 First name <input type="text"/>	1.12 Carer's mob no. <input type="text"/>	
1.4 Gender <input type="checkbox"/> M <input type="checkbox"/> F	1.13 <b>Secondary supply address</b> Holiday, school, respite, workplace etc Make sure permanent address also completed <input style="width: 100%; height: 100%;" type="text"/> Postcode <input type="text"/>	
1.5 DOB <input type="text"/>		
1.6 NHS no. <input type="text"/>	1.14 Contact name <input type="text"/>	
1.7 Permanent home address <input style="width: 100%; height: 100%;" type="text"/> Postcode <input type="text"/>	1.15 Contact tel no. <input type="text"/>	
1.8 Tel no. <input type="text"/>	1.16 Dates at address (from and to) <input type="text"/> <input type="text"/>	
1.9 Mobile no. <input type="text"/>		
2 GP'S DETAILS		
2.1 Main practice name (not branch) <input style="width: 100%; height: 100%;" type="text"/>	2.3 PPD practice code <input type="text"/>	<b>3 CLINICAL CONTACT FOR QUERIES</b> 3.1 Contact name <input type="text"/> 3.2 Tel no. <input type="text"/> 3.3 Fax no. <input type="text"/>
2.2 Practice address <input style="width: 100%; height: 100%;" type="text"/> Postcode <input type="text"/>	2.4 Practice tel no. <input type="text"/>	
	2.5 Practice fax no. <input type="text"/>	
	2.6 PCT/LHB name (for charging purposes) <input style="width: 100%; height: 100%;" type="text"/>	
4 HOSPITAL OR COMMUNITY CLINIC DETAILS		
4.1 Name <input type="text"/>	4.3 Tel no. <input type="text"/>	4.6 Ward name <input type="text"/> 4.7 Ward tel no. <input type="text"/> 4.8 Date of discharge <input type="text"/>
4.2 Hospital or clinic address <input style="width: 100%; height: 100%;" type="text"/> Postcode <input type="text"/>	4.4 Fax no. <input type="text"/>	
	<i>For hospital discharge complete sections 4.5 - 4.8</i>	
	4.5 Patient hospital no. <input style="width: 100%; height: 100%;" type="text"/>	
5 LONG-TERM OXYGEN THERAPY		
5.1 Litres/min <input type="text"/>	6 <b>AMBULATORY SERVICE (PORTABLE)</b> Specialist assessment needed prior to ordering	
5.2 Hours/day <input type="text"/>	6.1 Litres/min <input type="text"/>	7 <b>SHORT BURST OXYGEN THERAPY</b> 7.1 Litres/min <input type="text" value="15"/> 7.2 Mins/day <input type="checkbox"/> 15 <input type="checkbox"/> 30 <input type="checkbox"/> 60 <input checked="" type="checkbox"/> Up to 120 <input type="text"/> Other (specify) <input type="text"/> 7.3 <b>Services</b> <input type="checkbox"/> Nasal cannulae <input checked="" type="checkbox"/> Mask % <input type="text" value="100"/> <i>If unsure, contact supplier</i> <input type="checkbox"/> Interim supply pre-assessment
5.3 <b>Services</b>	6.2 Hours/day <input type="text"/>	
<input type="checkbox"/> Nasal cannulae	6.3 <b>Services</b>	
<input type="checkbox"/> Mask % <input type="text"/> <i>If unsure, contact supplier</i>	<input type="checkbox"/> Nasal cannulae	
<input type="checkbox"/> Interim supply pre-assessment	<input type="checkbox"/> Mask % <input type="text"/>	
<input type="checkbox"/> Humidification <i>Not usually for flow rates below 4l/min</i>	<input type="checkbox"/> Conserving device contra indicated	
	<input type="checkbox"/> Lightweight equipment <i>Only where patient assessed</i>	
8 DELIVERY DETAILS		
<input type="checkbox"/> Standard ( <i>Within 3 working days</i> )	9 <b>DECLARATION</b>	
<input type="checkbox"/> Next day ( <i>Clinical assessment services and hospital discharges only</i> )	I declare that the information given on this form for NHS treatment is correct and complete. I understand that if I knowingly provide false information, I may be liable to prosecution or civil proceedings. I also confirm that I am the registered healthcare professional responsible for the information provided.	
<input type="checkbox"/> Urgent response ( <i>4-hour delivery</i> ) <i>Order only when clinically appropriate</i>	Name <input type="text"/>	Profession <input type="text"/>
	Signature <input type="text"/>	Date <input type="text"/>

# Home Oxygen Order Form (HOOF)

Guidance notes. Please read before completing order.



Home Oxygen Consent Form (HOCF): Must be completed. Consent by patient is **not** consent to treatment but the transfer of patient personal information to the supplier to support service delivery, as required by the Data Protection Act 1998 and is essential when patient first receives home oxygen service. **Important: HOOF must be accurate and legible.**

## 1 PATIENT'S DETAILS

- 1.5 Date of birth will confirm if the order is paediatric.
- 1.10 Include carer's details, as appropriate.
- 1.13 Only complete this if delivery is to temporary address (eg holidays, respite care) or alternative address (eg school or workplace).
- 1.16 Insert dates for period that patient is away from permanent address and needs supply for these dates.
- 1.17 **Important:** Insert Clinical Code if known. Use correct code from list below.

01	Chronic obstructive pulmonary disease (COPD)	12	Paediatric interstitial lung disease
02	Pulmonary vascular disease	13	Chronic neonatal lung disease
03	Severe chronic asthma	14	Neuromuscular disease
04	Primary pulmonary hypertension	15	Paediatric cardiac disease
05	Interstitial lung disease	16	Neurodisability
06	Pulmonary malignancy	17	Chest wall disease
07	Cystic fibrosis	18	Other primary respiratory disorder
08	Palliative care	19	Obstructive sleep apnoea syndrome
09	Bronchiectasis (not cystic fibrosis)	20	Cluster headache
10	Non-pulmonary palliative care	21	Other
11	Chronic heart failure	22	Not known

- 1.21 **Important:** Provide any additional information helpful to the supplier (eg patient has disability/frail/language needs).

## 2 GP'S DETAILS

- 2.2 Must include main practice address, not branch address, for billing.
- 2.3 For GP practice order, add practice code.
- 2.5 Fax number is required for oxygen supplier to confirm receipt of order.
- 2.6 Add name of PCT/LHB to charge for service(s) ordered.

## 3 CLINICAL CONTACT FOR QUERIES

Include contact name, telephone and numbers for supplier to contact clinic for queries.

## 4 HOSPITAL OR COMMUNITY CLINIC DETAILS

- 4.5 **Important:** For hospital discharge order, please confirm if supply is needed next day after discharge (Box 8).

## 5 LONG-TERM OXYGEN THERAPY (LTOT)

Prescribe LTOT for patient needing oxygen continuously (usually at least 15 hours a day, including at night). **Assessment recommended before LTOT. Complete boxes 5 and 6 if order is paediatric. Important: LTOT order does not include equipment to support supply outside the home; if needed, also complete Box 6. Infants on LTOT will usually need ambulatory oxygen.**

- 5.1 **Important:** Must insert correct flow rate in litres per minute.
- 5.2 **Important:** Must insert correct number of hours of use for every 24 hours.
- 5.3 Please indicate if mask or cannulae required.  
**Masks: Supply will be at appropriate flow rate to % prescribed. If unsure, contact supplier.**  
Humidification not usually recommended for flow rates below 4 litres per minute.

## 6 AMBULATORY SERVICE (PORTABLE)

Assessment needed prior to ordering.

- 6.1 Flow rate may be same as LTOT but hours of use will be different.
- 6.3 Confirm supply of mask (%) or cannulae. If conserving device is requested, cannulae will be supplied.  
If conserving device is contra-indicated, tick box.  
Lightweight equipment: **Standard ambulatory equipment will be provided unless patient assessment states a specific need for lightweight equipment.** The 'lightweight' option is indicated for patients who are mobile and need to leave the home on a regular basis but find that the weight of the standard ambulatory oxygen cylinder affects their breathing and/or mobility.

## 7 SHORT BURST OXYGEN THERAPY (SBOT)

Prescribe SBOT for patient needing oxygen intermittently for up to two hours in a day.

- 7.3 Confirm supply of mask (%) or cannulae.

## 8 DELIVERY DETAILS

Supplier	Tel	Fax	Service Regions
Air Products	0800 373 580	0800 214 709	North West, Yorks & Humberside, East Midlands, West Midlands, North London, Wales
Air Liquide	0500 823 773	0800 7814 610	South London, South Central, South East Coast
Air Liquide	0808 202 2229	0191 4974 340	North East, South West
BOC Healthcare	0800 136 603	0800 1699 989	East of England