

# Fact sheet

# Cluster Headache

Dr Giles Elrington. Updated January 2012

"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. I cannot imagine a more severe pain."

## What is cluster headache?

Cluster Headache describes attacks of severe one-sided pain in the head, usually around the eye. The pain is associated with autonomic change in or around the eye. This means watering (including a runny nose), redness, eyelid closure, a small pupil, skin redness or sweating. Periods of attacks are known as bouts in which the pain is clustered (hence the name) over a few weeks or months.

## Who gets cluster headache?

Cluster Headache is relatively uncommon but affects at least 4 in 1000 people. Men are more often affected than women (unlike most other types of headache). Women with cluster say it's worse than childbirth. It can start at any age, most often in younger adults.

## What are the different types of cluster headache?

The more common type (90%) is episodic cluster headache. This comes and goes, at worst a few bouts a year lasting, more often between twice a year and once on two years. Intriguingly, bouts are commoner in spring and in autumn.

Chronic cluster is fortunately less common (10%) and simply means the same sort of pain, going on for six months or more. In chronic cluster the pain may be continuous.

## What are the symptoms of cluster headache?

Cluster Headache is extremely painful – so severe that it has been called 'suicide' headache.

Within a bout, pain always stays on the same side. A minority of patients find cluster changes sides from bout to bout.

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 up to an hour but can be anything between 15 minutes and 3 hours.

In contrast to migraine, when most people want to rest during an attack, the pain of cluster pain tends to make the patient restless or active, even to the point of banging their head on the wall.

Pain is often at the same time every night ("alarm clock pain") and typically also occurs within minutes of drinking alcohol, so it is unusual to see a cluster patient who carries on drinking through a bout.

## Do I need any tests?

No. One study, surprisingly, showed an excess of pituitary gland abnormalities in people with cluster, leading some experts to scan the brain and pituitary in patients with new cluster headache.

People taking verapamil for cluster headache are often recommended to have an electrocardiogram before and during treatment with verapamil, to rule out heart rhythm problems which can be caused or worsened by this drug.

## What causes cluster headache?

Cluster, like migraine, is a primary headache, in other words it arises from an error of nerve function. Using a computing analogy, it is a software problem. A minority of experts see cluster as a variant of migraine, though unlike migraine cluster is not worsened by repetitive acute treatments, and localizes to a different part of the brain, the midbrain, also known as the posterior hypothalamus or peri-aqueductal gray matter. This fits in with the sleep and seasonal

variation. Migraine arises lower down, in the brainstem or trigeminal nucleus.

## What are triggers for cluster headache?

Usually there are no triggers, but alcohol can bring on an attack though zero alcohol does not abolish the bout. Cluster associates with smoking, though quitting smoking has not been shown to help. Other recognised triggers include exercise and elevated environmental temperatures. Other than not drinking alcohol, and the fact we all need to be non-smokers, addressing triggers is much less helpful for cluster than it is for migraine.

## Will it get better?

Fortunately for many sufferers, particularly those with chronic cluster headache, cluster often improves in later life. Bouts of episodic cluster are by definition guaranteed to improve naturally, though tend to recur in the fullness of time.

## What can I do to help myself?

Ordinary painkillers do not work and simply “muddy the water” with side effects. Effective treatment requires medical advice as prescription-only drugs are needed.

Cluster is uncommon so many non-specialist doctors have never seen a case. It may therefore be helpful to download selectively from [www.ouchuk.org](http://www.ouchuk.org) (the organization to understand cluster headache) or bring this factsheet to show to your doctor; this requires tact as many doctors are understandably wary of second opinions from Dr Google!

## What treatment can I take?

Either you put up with the excruciating pain, or take medication.

Unless you have a very special GP, you will need to see an expert in headache. Such experts are often saddened to encounter people with decades of cluster headache who have had neither diagnosis nor treatment for this seriously painful condition.

For episodic cluster, the usual starting regime is:

- Sumatriptan 6mg injection for each episode of pain, taken as soon as possible after the start of pain. This normally works within minutes.
- Prednisolone 70mg daily after breakfast for a week with brisk taper thereafter to zero. This aborts the bout in 70% and allows time for verapamil to start working.
- Verapamil 80mg or 120mg three times daily, if electrocardiogram is normal. Continue until the bout is over – which is normally obvious to the patient.

Many respond to verapamil 120mg 3 times daily, but higher doses, up to 360mg three times daily may be necessary. An electrocardiogram (ECG) should be taken 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 tapered over a few 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) acid indigestion and flushing can happen. Good dental care (flossing) is important as gum bleeding from gum overgrowth (gingival hyperplasia) can occur.

## Other Cluster Treatments

High dose (100%) oxygen is a possible alternative to sumatriptan, though can be a fiddle to set up. The correct kit is required. 100% oxygen is 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. If you live in Scotland, your GP will write a prescription for oxygen and you will need to obtain a high flow regulator. Some people find that oxygen simply time-shifts the attack.

Triptans other than subcutaneous sumatriptan are best avoided as their latency to benefit (1-2 hours) is too long.

Alternatives to verapamil include methysergide, valproate, lithium, and melatonin.

Greater occipital nerve (GON) block is worth considering; as is a trial of indometacin as cluster can be mistaken for a hemicrania.

### Referrals

Refractory cases may be considered for neurosurgical treatment with brain or occipital nerve stimulation.

Non-specialists should have a low threshold for referring patients with cluster headache to an expert.

### 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 National Migraine Centre Doctor.*

## 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>

<p>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:</p> <ol style="list-style-type: none"> <li>1. information about <u>my condition/condition of the patient named above</u>* 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),</li> <li>2. 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,</li> <li>3. 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),</li> <li>4. 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</li> <li>5. information will also be shared with my electricity supplier/distributor where electrical devices have been installed.</li> <li>6. From time to time, I may be contacted to participate in a patient satisfaction survey/audit. <i>(should you wish not to participate please inform your HOS supplier)</i></li> <li>7. I understand that I may withdraw my consent at any time (at which point my HOS equipment will be removed)</li> </ol>
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* Delete as applicable			
<b>Patient's signature</b>	<input type="text"/>	<b>Date</b>	<input type="text"/>
(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>	<input type="text"/>	<b>Name</b>	<input type="text"/>
<b>Relationship to patient</b>	<input type="text"/>	<b>Date</b>	<input type="text"/>
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			
<b>Clinician's signature</b>	<input type="text"/>	<b>Date</b>	<input type="text"/>
<b>Name</b>	<input type="text"/>		

# 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 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 <i>Make sure permanent address also completed</i> <input type="text"/> Postcode <input type="text"/>	
1.5 DOB <input type="text"/>	1.14 Contact name <input type="text"/>	
1.6 NHS no. <input type="text"/>	1.15 Contact tel no. <input type="text"/>	
1.7 Permanent home address <input type="text"/> Postcode <input type="text"/>	1.16 Dates at address (from and to) <input type="text"/> <input type="text"/>	
1.8 Tel no. <input type="text"/>		
1.9 Mobile no. <input type="text"/>		
<b>2 GP'S DETAILS</b>		
2.1 Main practice name (not branch) <input type="text"/>	2.3 PPD practice code <input type="text"/>	<b>3 CLINICAL CONTACT FOR QUERIES</b>
2.2 Practice address <input 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 type="text"/>	
<b>4 HOSPITAL OR COMMUNITY CLINIC DETAILS</b>		
4.1 Name <input type="text"/>	4.3 Tel no. <input type="text"/>	4.6 Ward name <input type="text"/>
4.2 Hospital or clinic address <input 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 type="text"/>	
4.7 Ward tel no. <input type="text"/>	4.8 Date of discharge <input type="text"/>	
<b>5 LONG-TERM OXYGEN THERAPY</b>		
5.1 Litres/min <input type="text"/>	<b>6 AMBULATORY SERVICE (PORTABLE)</b>	
5.2 Hours/day <input type="text"/>	Specialist assessment needed prior to ordering	
5.3 <b>Services</b>	6.1 Litres/min <input type="text"/>	
<input type="checkbox"/> Nasal cannulae	6.2 Hours/day <input type="text"/>	
<input type="checkbox"/> Mask % <input type="text"/>	6.3 <b>Services</b>	
<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>If unsure, contact supplier</i>	
<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>	
<b>7 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)	
	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	
<b>8 DELIVERY DETAILS</b>		
<input type="checkbox"/> Standard (Within 3 working days)		
<input type="checkbox"/> Next day (Clinical assessment services and hospital discharges only)		
<input type="checkbox"/> Urgent response (4-hour delivery) <i>Order only when clinically appropriate</i>		
<b>9 DECLARATION</b>		
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.		
Name <input type="text"/>		Profession <input type="text"/>
Signature <input type="text"/>		Date <input type="text"/>

