NOTTINGHAMSHIRE HOME OXYGEN PATHWAY FOR CLUSTER HEADACHES

Patient newly# diagnosed with cluster headache confirmed by Neurologist and suitable for oxygen therapy as acute treatment.

→ Neurologist/Specialist* to complete Initial Home Oxygen Risk Mitigation (IHORM) & Home Oxygen Consent Form (HOCF) with the patient, and to send prescription request for home oxygen supply (HOOF) directly to BOC.

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BOC to deliver first oxygen supply and to inform relevant local community Home Oxygen Service (HOS) of the new patient referring for "at home" risk assessment.

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HOS team to reiterate how to use, advise on safe use of oxygen, discuss and mitigate any risks.

If safe, continue prescribing: 100% oxygen short-burst, at a flow rate specified by Neurologist/Specialist (between 10-15 L/min) for 15-20 minutes at time with no daily limit via a non-rebreathing mask and a reservoir bag, and 1 static cylinder.

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HOS Team

1. Advise patient: if no effect after 20 minutes of high flow oxygen, probably no benefit to control cluster headache on this occasion and patient to consider other symptom control method.
2. Document in patient's medical record high flow oxygen treatment for cluster headache, add patient alert on SystmOne/EMIS and send standard letter to notify GP.
3. Alert Fire Brigade patient has oxygen cylinder in residence (if indicated on the EMHORT form).

If oxygen has no effect after 5 episodes of cluster headache patient should inform HOS with a view to review therapy and possibly removing home oxygen due to effectiveness failure.

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Patient reviewed after 6 -12 months by HOS team (face to face or by phone).

← Patient noted to have high cylinder usage or safety concerns.

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Possible chronic patient

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Consider high flow demand valve.

Update HOOF accordingly, if needed, requesting high flow demand valve and stating either chronic cluster headaches or patient safety reason.

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HOS to review patient after 6 -12 months (face to face or by phone).

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If no reports of insufficient effect or no high usage - continue with current delivery method.

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Possible episodic patient.

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HOS to review patient annually including risk, concordance and clinical effectiveness.
If the patient does not use the oxygen for a year, arrange removal.
Inform GP of removal.

Pre-existing users of oxygen for cluster headaches, when presented to the GP practice at new registration/relocation, OR patients advised oxygen via Advice & Guidance by local Neurologist, require referral from GP to HOS for oxygen safety assessment at home and prescription for oxygen.

* The prescriber i.e. Neurologist/Specialist needs to be registered with BOC portal www.bochop.co.uk

Information about commissioned Home Oxygen Services available within Nottingham and Nottinghamshire localities could be found on TeamNet. Please log into this online platform if you need an access to referral forms or to see contact details for the service providers in your local area.

GLOSSARY:

IHORM – Initial Home Oxygen Risk Mitigation Form. Introduced to reduce the risk of a serious incident occurring if medical oxygen is installed in a home environment. To be completed by the initiating Neurologist/Specialist in the clinic.

HOCF – Home Oxygen Consent Form. To be completed by the initiating Neurologist/Specialist in the clinic.

HOOF – Home Oxygen Order Form. To be completed by the initiating Neurologist/Specialist and sent via portal directly to BOC.

BOC – the British Oxygen Company. Supplies the oxygen directly to patients.

HOS - Home Oxygen Service Team. Contact details for each locality below:

Locality	Contact number	Email address
Bassetlaw	0177 727 4422	BassetlawHOS@nottshc.nhs.uk
Mansfield and Ashfield	0162 378 1891 mobile: 07971697510	homeoxygenservicemanda@nottshc.nhs.uk
Newark & Sherwood	0162 378 1891	homeoxygenserviceNandS@nottshc.nhs.uk
NNE	0115 844 0504	SoutNottsrespiratoryreferrals@nottshc.nhs.uk
Nottingham City	0115 883 3622	NCP.Respiratory@nhs.net
Notts West	0115 844 0510	NWcardiorespiratoryreferrals@nottshc.nhs.uk
Rushcliffe	0115 844 0504	SoutNottsrespiratoryreferrals@nottshc.nhs.uk

Non-rebreathing mask - a device used in medicine to assist in the delivery of oxygen therapy.

Static cylinder (DF) – holds 1360 litres of oxygen.

Cluster – attack between 1 & 8 times per day.

Cluster cycle – lasts weeks or months with remission periods.

Chronic – no remission periods or remissions that last less than a month at a time.

Episodic – attacks occur in periods lasting 7 days to a year and are separated by pain-free periods lasting 1 month or longer.

High flow demand valve - is a device that allows a patient to inhale 100% oxygen and is breath activated. It allows the high flow oxygen to be delivered using less oxygen, reducing the number of cylinders chronic patients need. It also stops the flow of oxygen if the patient falls asleep so maintaining safety and preserving oxygen supply.

From the clinical research there is no clear evidence that the demand valve has proven increased in efficacy for cluster headaches.

The high flow demand valve will only be available on the NHS for identified chronic sufferers.

If episodic patients wish to use a high flow demand valve, then they can be rented from BOC. The NHS cannot justify the cost of supplying demand valves to all cluster headache patients as there maybe years between episodes when an expensive valve is sitting in a patient's home not being used. Any consumables

required by patients who have bought their own demand valve should be supplied free of charge by BOC as part of the contract.

Standard Questions to be addressed by HOS at the follow up review at least annually (face to face or over the telephone):

Aim: to assess efficacy of home oxygen during a cluster headache attack.

“Does the high flow oxygen result in a definite reduction in the duration or the intensity of the attacks of cluster headache?”

- If clear benefit, continue with oxygen use.
- If no benefit (or very infrequent benefit, e.g. if oxygen helps with less than one quarter of the attacks) then remove the oxygen.
- If not clear, then reassess after 4 weeks, abstaining from using oxygen for 2 weeks then using oxygen for 2 weeks. Ask the patient to grade the duration and intensity of the attacks (e.g. with and without oxygen).

References:

- NICE Clinical guideline [CG150]. Headaches in over 12s: diagnosis and management. Last updated: 03/06/2025 (https://www.nice.org.uk/guidance/cg150)
- Wendy Bradford, NHS East Midlands Clinical Network, Flow diagram for East Midlands Demand Valve for Cluster Headache. December 2021.
- British Association for the Study of Headache, National Headache Management System for Adults 2019. (https://bash.org.uk/wp-content/uploads/2023/02/01_BASHNationalHeadache_Management_SystemforAdults_2019_guideline_versi.pdf)