Advice on Oxygen treatment for Cluster Headache - London

Information for Patients and Carers

High flow short-burst oxygen is effective for treating attacks in some patients with cluster headache. You should be offered a trial of high flow short-burst oxygen as soon as you have been diagnosed with cluster headaches.

Oxygen can be ordered for you by your doctor, either GP or neurologist, or an oxygen specialist on their behalf, provided the order forms are completed appropriately. If your doctor needs information on how to do this, a leaflet from the London Clinical Oxygen Network titled ‘Advice on Oxygen Treatment for Cluster Headache in Adults; Information for GPs and Neurologists’ is available at https://www.networks.nhs.uk/nhs-networks/london-lungs.

You will also need to sign a form giving consent for your information to be shared so that the company providing oxygen to you in your home has the details they need, and so that you can be contacted by your local oxygen specialist nurse. If possible your local oxygen specialist nurse should review you to explain about having oxygen in your home and to make sure this is safe. You should expect to be asked whether you smoke.

You should be provided with:

- Two free-standing cylinders to use at home (or work) so you can easily switch to the second cylinder when the first cylinder is empty and order a replacement. Each cylinder can treat between 8-30 attacks depending on the speed of response.
- Ambulatory cylinders so you can use oxygen easily when outside the home (carried in your car and/or in a storage backpack). These cylinders are much smaller so only contain enough oxygen to treat a small number of attacks (again depending on the speed of response).
- A mask called a non-rebreath mask which has a reservoir bag and is used with the two holes covered.

As soon as you know an attack is starting turn the oxygen on to 15 litres per minute and then after a few minutes turn it down to around 6 to 8 litres per minute, sufficient to keep the little reservoir bag inflated. If successful, an individual attack should be aborted within 15-20 minutes. If the attack is successfully stopped, you should stay on the oxygen for 5-10 minutes after the pain has gone to “mop up” the attack and prevent possible rebound, which some patients find is a problem. If the attack is not stopped within 20 minutes you are unlikely to get relief for that attack by continued use and you should turn off the oxygen. This does not mean that further attacks will not respond to oxygen and it is worth trying oxygen again at the start of the next attack.

If you do not find oxygen helpful, or do not want to continue to use it, you should let the person who ordered the oxygen know so that the oxygen can be cancelled. Your GP and neurologist also need to know this so that they can review your treatment.

Remember NEVER smoke around or while using oxygen and keep oxygen away from naked flames like candles, open or gas fires and cookers. If you smoke, quitting is one of the best things you will ever do for your health. More information and free support is available at www.nhs.uk/smokefree.

More information is available from OUCH (Organisation for the Understanding of Cluster Headache) at www.ouchuk.org. OUCH is a UK Charity whose aim is to raise awareness of cluster headache within the medical profession and the public and to offer support and guidance to sufferers and their families.