

## Oxygen for Cluster Headaches: A Guide

This guide was compiled by Clusterbusters, Inc., based on the indispensable previous contributions of many, many individuals and organizations.

It is provided for information purposes only; advice on the treatment or care of an individual patient should be obtained through consultation with a licensed physician who has examined that patient and is familiar with that patient's medical history.

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## 1. Introduction

Oxygen is an essential tool for dealing with cluster headaches. For most people with CH, oxygen when properly used will abort an attack within 15 minutes—often in less time than that. Unlike many other prescribed abortives, oxygen has no negative side effects. Virtually the only people who cannot use oxygen to treat CH are those with serious lung disease or other similar conditions.

Put simply: Oxygen can change your life—or even save it. And yet, many people with CH have never tried oxygen at all. A major recent study reported that 34 percent of people in the US with CH had never tried oxygen; it also reported that half of the CH sufferers using oxygen never received instruction in its proper use.<sup>1</sup> [See endnotes for citations and links where available]

If you are one of these people, you are missing what can be a very important, highly effective way of treating your CH.

*And, oxygen might work for you even if you have tried it in the past without success. A lot has been learned about increasing success at aborting with oxygen. Before giving up on oxygen, please consider the suggestions below, including higher flow rates, a demand valve delivery system, a top-quality mask specifically designed for people with CH, and the perhaps a different breathing strategy. To read a special section about*

these specific ways to potentially increase the effectiveness of oxygen, click [here](#).

Medical oxygen can (and should) be prescribed by your doctor. However, doctors are often not as knowledgeable as we might want them to be about oxygen [O<sub>2</sub>] as a CH abortive: 44 percent of O<sub>2</sub> users in the study above had to suggest it to their doctors themselves. You must advocate for yourself in this regard. (See the discussion below, “[Thoughts about Talking to Your Doctor](#)”).

45 percent of the people in that study had to find their own source for oxygen because a doctor would not prescribe it. Those who find their own source most often create their own systems using welding oxygen. For more information about this, including cautions regarding welding oxygen, see the section below, “[About Welding Oxygen](#).”

O<sub>2</sub> can be used in addition to other preventive and/or abortive medications prescribed by your doctor. In fact, the study that was mentioned above reported: “An interesting and unexpected finding from the survey is that oxygen may actually enhance the efficacy of non-oxygen abortives like triptans ... When oxygen is combined with another abortive more patients have complete pain relief after a shorter duration of time...”<sup>2</sup>

There do not appear to be any harmful interactions with commonly prescribed CH drugs as long as your cardiopulmonary functions are normal.

## **2. The Effectiveness of Oxygen [O<sub>2</sub>] for Aborting Cluster Headaches**

The effectiveness of oxygen as a CH abortive has been demonstrated in controlled medical research, and reported in prestigious journals. The leading study is “High-Flow Oxygen for Treatment of Cluster Headache,” which was published in the *Journal of the American Medical Association* in 2009.<sup>3</sup>

In this study, an O<sub>2</sub> flow rate of 12 liters per minute [lpm] was used. That is now considered a relatively low flow rate, and yet 78 percent of the participants in the study (which included both chronic and episodic CH patients) experienced significant relief within 15 minutes. No side effects were reported. (In an earlier study, even lower flow rates—7 lpm—produced positive results.)

Based on this research, American and European treatment guidelines list inhalation of oxygen as the abortive of choice for cluster headaches. The guidelines state: “The first option for the treatment of acute attacks of cluster headache should be the inhalation of 100% oxygen with at least 7 liters/min over 15 min . . .” (Sumatriptan injections are also listed as a primary abortive option.)<sup>4</sup> Note that 7 liters per minute is now widely considered to be too low of a flow—and the summary chart of recommendations within the guidelines calls for 15 lpm.

### 3. Basics of Use and Setup



Setting up and using an oxygen system is very easy and safe—much simpler than you might imagine.

To abort a CH attack, you want to inhale highly concentrated oxygen at a flow rate of 12-15 liters per minute or more. A high flow rate keeps the reservoir bag that is attached to your mask full of oxygen so that you can breathe in the O<sub>2</sub> deeply, without interruption.

Increasingly, people with CH are using higher flow rates, of 25 to 60 lpm, and finding that those flow rates result in faster and generally more effective aborting of attacks. You can read more about flow rates [here](#).

It is important to begin using your oxygen as soon as possible after the very first sign of a CH attack. The sooner you start, the more effective the abort is likely to be. (Many people find that quickly drinking an “energy drink”—RedBull, Monster, 5-Hour Energy, or something else that’s high in caffeine and taurine—just before starting on the oxygen seems to reduce the time required to abort the attack.)

Breathing techniques vary (they are discussed in more detail [here](#)). In general, with a flow rate of 15 lpm or less, breathing more rapidly and more deeply than usual is recommended. Using higher flow rates, many prefer the hyperventilation method described [here](#). 20 minutes of inhalation is the recommended maximum time at one “sitting”—if that does not abort an attack, it is generally recommended to wait five to ten minutes and then try again. However, even breathing oxygen continuously for one or two hours does not appear to pose a significant health risk to individuals with normal cardio-pulmonary functions. While we don’t recommend 2 hours of oxygen use to abort a cluster headache, you will need to experiment and establish what works for you individually.

You want to use a mask or other device that delivers the oxygen to you without including any outside air—a *non-rebreather mask* is preferred, but you can also use a mouthpiece. To read more about properly using a mask, see section 6 below, “[More about Masks](#).” Many people have found that they get best results with the O2ptimask, which is designed specifically for people with CH.

Since some people fall asleep when an attack is aborted, you should not use a strap to hold the mask to your face. If your mask has a strap on it, you can cut it off, or simply not use it. Hold the mask firmly against your face with your hand.

After you have aborted an attack, anecdotal reports suggest you should continue inhaling oxygen for several minutes more after ending the attack. Many find continued breathing of oxygen for a period of time after the attack has ended (approximately as long as the time it took for you to abort the attack) to be very beneficial in preventing soon-recurring attacks. This is highly variable, some find a few minutes helpful and some stay on the O2 for up to 20 minutes. Experiment for yourself: vary the time and even the flow rate, individualize this by trial and error.

DO NOT SMOKE or use any kind of open flame around oxygen. Oxygen is not combustible but it is a powerful accelerant. Flame and/or fire can lead to an explosion of the tank itself! Don’t be afraid, but don’t be foolish either. ALSO, oxygen can saturate your clothing, bed sheets, etc., and then catch on fire when you light a match. Be very careful and wait at least 30 minutes after using oxygen before smoking. It is wise to be sure that the room where you use oxygen is well ventilated.

If your oxygen is provided by an oxygen-supply company, fully discuss all safety precautions with that provider.

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For the safety of emergency personnel and neighbors, your local emergency services organizations (the fire department, in particular) should be made aware that you have an oxygen tank in your home or apartment, and if you use O<sub>2</sub> in your office at work you should inform your organization and place a warning label on the door to your office like this one:



#### **4. Getting Your Equipment**

Your doctor should prescribe oxygen [O<sub>2</sub>], which will then be delivered to you in cylinders (“tanks”) by a medical oxygen supplier. The supplier should also provide you with a regulator and a non-rebreather mask. Many people with CH prefer to get their own higher-quality mask and, in some cases, their own higher-flow regulator. There is more information about this in the next sections.

The doctor’s prescription will typically be quite simple, just stating that you should receive O<sub>2</sub> at 12-15 lpm with a non-rebreather mask. You can work with the oxygen supplier to get what you need. It is recommended that the prescription should state: “As needed for cluster headaches.” (See the sections below, [“Thoughts about Talking to Your Doctor”](#) and [“Working with Your Oxygen Supplier.”](#))

You will want to have at least one large oxygen cylinder—more than one is much better—and at least one smaller, more portable cylinder—again, more than one is better. Remember that tanks of different sizes may require different types of regulators regulators, so be sure that your supplier provides the proper type. To read more about this, see the section below, [“More about Cylinders/Tanks.”](#)

**Beware:** If the prescription you receive is for a low flow rate or does not specify a flow rate, a provider might give you a “concentrator” instead of a tank or tanks. A concentrator is a machine that creates oxygen out of room air. *Concentrators are essentially useless for aborting cluster*

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*headaches*, because they produce low flows and less than 100 percent pure O<sub>2</sub>, so be sure this is not what you are going to receive. (A very small number of people with CH do report that they can abort using a concentrator, but it is very far from the best option.)

This is a concentrator, which you do not want.



## **5. More about Flow Rates and Regulators**

The study reported above in the *Journal of the American Medical Association* [5](#) used flow rates of 12 liters per minute [12 lpm]. Most people with CH prefer at least 15 lpm. (Generally, a regulator that goes to 12 lpm will go to 15 lpm.) Some can use lower flow rates, at least during their first periods of using O<sub>2</sub>. *The issue is that the reservoir bag attached to your mask should fill quickly enough that you can breathe deeply and steadily without waiting.*

Increasingly, people with CH are finding that higher flow rates, of 25 – 60 lpm, work best for them, insuring that they always have enough oxygen coming through the system to inhale deeply. Higher flow rates also support the hyperventilation breathing method that many people with CH prefer (see “[Inhaling Oxygen for Maximum Effectiveness](#),” below).

You might have to order a higher-flow regulator for yourself (some people have been able to acquire prescriptions for higher-flow regulators from their physicians).

The demand valve system, discussed [here](#), allows for uninterrupted flow of oxygen.

Different size tanks require different types of regulators. So don't order a regulator until you know what kind of tank you have.

## Ordering a Regulator

Many people order a regulator from eBay. Go to [www.ebay.com](http://www.ebay.com) and type [oxygen regulator] (without the brackets) into the search window. Here's a link [*Note about links: We have tried throughout this document to insure that links are current and functional. However, things change.*]

[http://www.ebay.com/sch/i.html?from=R40&trksid=p5197.m570.l1311&\\_nkw=medical+oxygen+regulator&\\_sacat=See-All-Categories](http://www.ebay.com/sch/i.html?from=R40&trksid=p5197.m570.l1311&_nkw=medical+oxygen+regulator&_sacat=See-All-Categories)

Many internet suppliers also sell regulators. Here are some examples. The first three sell regulators of 25 lpm or more, as well as 15 lpm regulators.

Linde Healthcare

[http://www.lifegas.com/gas\\_devices\\_and\\_therapies/special\\_oxygen\\_needs.asp](http://www.lifegas.com/gas_devices_and_therapies/special_oxygen_needs.asp)

Mada Medical

<http://madamedical.com/>

Flotec Respiratory Products

[http://www.floteco2.com/htm/Products/Regulator/Regulator\\_RW\\_100-300\\_Catalog\\_Imag...](http://www.floteco2.com/htm/Products/Regulator/Regulator_RW_100-300_Catalog_Imag...)

Tina's Homecare

[http://www.tinashomecare.com/oxygen\\_therapy\\_oxygen\\_regulators.htm?gclid=CMP24tOb...](http://www.tinashomecare.com/oxygen_therapy_oxygen_regulators.htm?gclid=CMP24tOb...)

## **6. More about Masks**

The O2ptimask, designed specifically for people with CH, is strongly recommended by those who have used it. See more about that mask here: <http://www.clusterheadaches.com/khxc/> In Europe, you can order the O2ptimask at

<http://headachemasters.com/product.asp?product=3>

With a standard non-rebreather mask, there are two things you should consider doing:

1. Most non-rebreather masks have a set of holes on each side of the mask. At least one set of holes typically has a gasket in it that closes when you breathe in and opens when you breathe out (a "flapper valve"). Often there is no gasket—just holes—on one side. You should consider closing these holes so you breathe in only the oxygen from your tank, with no outside air mixed in. You can put tape on them to close them permanently, or just put your thumb



over them when you breathe in, and take your thumb off when you breathe out.

2. Consider cutting off any elastic strap that would hold the mask to your face, for two reasons: first, since many CH users can fall asleep while they're using oxygen, they will continue draining oxygen from their tank if the mask is still on; second, if they do fall asleep and the mask stays on, they might inhale oxygen for too long, which can in theory cause lung damage or suffocation.

A tight mask seal is very important. Facial hair, or a mask that is too large for the face, can interfere with getting a tight seal. Masks come in different sizes. Be sure you get one that's the right size for your face. Note that the O2ptimask comes in different sizes.

Also, some people can find that a mask feels uncomfortable, or even a little claustrophobic, or they can't get a tight-enough seal. You can remove the mask and breathe directly from the plastic valve. It is also effective to use a tube or "mouthpiece" for breathing. That tube is illustrated in the photo below:



With an O2ptimask, the mask itself can be removed, leaving a breathing tube you can use (it is shorter than the one shown in the illustration).

You should clean your mask regularly, and also make sure that the flapper valves in the mask are working properly. A good method of cleaning your mask is to use a benzalkonium chloride antiseptic towelette. Benzalkonium chloride is a rapid acting surface disinfectant and detergent that is active against bacteria, certain viruses, fungi, yeasts, and protozoa. Benzalkonium chloride towelettes come in packets available over the counter at any drugstore, and also available at many online shopping sites.

If you are hypersensitive to cleaning agents, dipping a clean paper towel or tissue in a mild solution of a hypoallergenic soap will work equally well in keeping your mask clean. Once you've cleaned your O2 mask, place it inside a ziploc bag to keep it free of dust and lint when not in use.

In a worst-case scenario of an unhelpful supplier, you might get nasal cannula (two tubes that go into your nostrils) instead of a non-rebreather mask. Like the concentrator discussed above, these are generally useless for dealing with cluster headaches.

NEVER, under any circumstances, breathe directly from the tank itself—it is at extreme high pressure and is very dangerous. There is no way to do that safely.

### Ordering a Mask

*[The links below were all working at the time this paper was posted. If any of them are no longer working, we apologize for your inconvenience.]*

You can order an O2ptimask at <http://www.clusterheadaches.com/khxc/>

You can order non-rebreather masks through eBay. Go to [www.ebay.com](http://www.ebay.com) and type in [non-rebreather mask] (without the brackets). Here's a link: [http://www.ebay.com/sch/i.html?from=R40&trksid=m570.12736&nk\\_w=non-rebreather+mask](http://www.ebay.com/sch/i.html?from=R40&trksid=m570.12736&nk_w=non-rebreather+mask)

You can find standard non-rebreather masks at many internet locations. Enter the words “non-rebreather mask” into a search engine to find suppliers. Note that these masks are quite inexpensive, so if you see a price quoted of more than a couple of dollars, it is probably for a case of masks, not just for one.

## **7. More about Cylinders/Tanks**

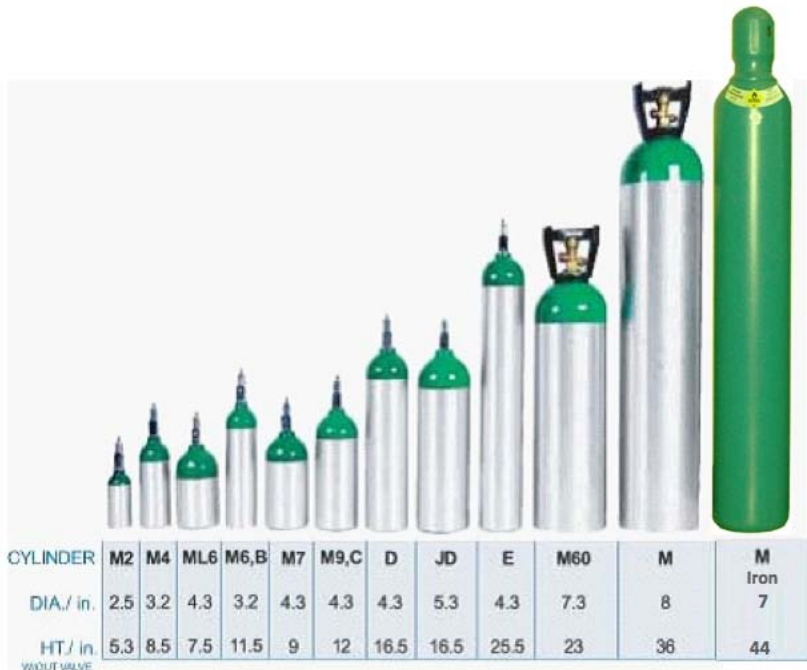
Large cylinders/tanks are generally “M” size; smaller cylinders are generally “E” size.

As you can see from the table below (and the relative sizes), an M tank contains many times more oxygen than an E tank. At 15 liters per minute, an M tank will provide approximately 198 minutes of oxygen (approximately 10 20-minute sessions). At 15 liters per minute, an E tank will provide approximately 35 minutes of oxygen, enough for less than two 20-minute sessions. (Here is a link to an online calculator

based on flow rates:

<http://www.monroecc.edu/depts/pstc/backup/paraoxca.htm>)

It's wise to keep a log containing the flow rate and number of sessions you are able to get from the first cylinder, and then then calculate how long your supply should last.



Tank Type	Tank Pressure (psig)	Cubic Feet	Nom. OD (inches)	Nom. Lgth (inches)	Nom. Wt. Empty (lbs)
H	2015	251	9.04	51.00	130
M	2015	125	7.00	43.00	75
E	2015	20	4.14	25.75	16
D	2015	10	4.14	16.75	10

If you are using a lot of oxygen (for example, because you are aborting attacks frequently or because you're using a very high flow rate), you can go through even a large tank quite quickly. Many oxygen prescriptions will just specify oxygen without specifying the size or number of tanks,

essentially leaving that up to you and your supplier. Two or more large tanks and two or more small tanks are desirable.

The large tanks are quite heavy (about 70 pounds) and not portable. You will almost certainly want at least one smaller tank for your car or for work (or for anyplace where you are likely to be out of immediate access to your larger tanks). Since the smaller tanks run out quickly, it is wise to have more than one.

(You can also create a highly portable system that can fit into a backpack. See more about that [here](#).)

You can buy a stand, or a wheeled cart or “caddy,” to hold your tanks—or some medical suppliers will provide them. More about where to purchase them [here](#).



**Use great caution** when storing or transporting tanks—nowhere near an open flame; and nowhere where they can fall, get rolled around, or otherwise become damaged (for example, where the valve could be broken off).

## **8. Inhaling Oxygen for Maximum Effectiveness**

It is always valuable to get as much O<sub>2</sub> as possible into your lungs, and to remove as much room air as possible from your lungs. People with CH use many strategies to accomplish that, and you should try different methods to find what works best for you. There are many discussions of breathing strategies on the message boards at [www.clusterheadaches.com](http://www.clusterheadaches.com), and you can find them by typing an appropriate key word such as *breathe*, *inhale*, or *hyperventilate* into the search engine there. With a 15 lpm regulator, the breathing strategy will typically involve breathing more rapidly and more deeply than your

normal breathing, and being sure to exhale fully each time. Your respiration rate should be 24-30 in/out breath cycles per minute, whereas a typical “normal” respiration rate is between 12 and 20 cycles per minute. (Most people with CH find it difficult to count their respiration cycles while they’re trying to abort an attack, so these numbers are more to give you an idea of the difference between “normal” respiration rates and how you might breathe in O2.)

Some suggest breathing in through the nose if possible (if you’re not too congested), and out through the mouth. You might try this to see whether it improves your success at aborting your attacks.

At flow rates of 25 lpm and higher, or with a demand valve, it may be feasible for you to breathe more assertively, forcibly exhaling as much air as possible from the lungs and inhaling as fully as possible. A “hyperventilation” method has been used with success by some people. To read more about that method, enter the word *hyperventilate* into the search engine at the message board at [www.clusterheadaches.com](http://www.clusterheadaches.com). Here is a link to one entry (we cannot guarantee that the link will always be operative, but it was at the time this paper was published): See particularly the fifth entry, by “Batch,” on this page:

<http://www.clusterheadaches.com/cgi-bin/yabb2/YaBB.pl?num=1313766756>

CAUTION should be used with hyperventilation and any of the breathing strategies described here, if you choose to try them.

Many people with CH report that they abort their attacks more rapidly when they quickly drink an “energy drink”—such as RedBull, Monster, or 5-Hour Energy, containing caffeine and taurine—at the first sign of a CH attack, followed by immediately using O2.

## **9. Other Equipment You Might Want**

### Longer Tubing

Many people like to use longer tubing, so that they can pace while using O2. You can purchase longer tubing, or adapters to extend additional tubing. To find sources, enter the words [oxygen tubing] (without the brackets) into an internet search engine.

## Demand Valve

A **demand valve system** uses a special valve with an additional fitting on a regulator to provide an uninterrupted flow of oxygen when needed—no need to wait for a reservoir bag to fill up. The oxygen flow shuts off when you are not actively breathing through the mask, optimizing the tank. A demand valve system can be expensive (around \$350 or more), but many recommend it highly, particularly when a more “standard” oxygen setup is no longer working at full effectiveness.

The demand valve is highly recommended for those who have not had success in the past at aborting with oxygen. Because of the cost, new oxygen users might want to try the more standard system first. See information [here](#) about where to get a demand valve system. (You will probably need a prescription to rent a demand system from some an oxygen supplier.)

(A clinical trial of the use of the demand valve system for cluster headache patients was recently completed. For more information, see <http://clinicaltrials.gov/ct2/show/NCT01298921>)

## Humidifier (“Bubbler”)

The oxygen in a tank is very dry, so much so that some people experience irritation in their nose, mouth, throat, or lungs when using it. A “bubbler” or humidifier passes the oxygen through water to add some moisture. Be careful, though, because not all humidifiers will work properly at the higher flow rates generally required to abort cluster headaches. Check with your oxygen supplier before attaching a bubbler. According to one publication, “a good rule of thumb is to look for a 3 to 6 psi rating with a ‘pop-off’ pressure relief valve, and a diffuser that generates smaller bubbles.”<sup>6</sup>

If you fill your own bubbler, be sure to use sterile distilled water. Tap water contains impurities such as calcium and iron that will eventually coat the inside of your tubing and your mask and may promote bacterial growth, which must be avoided.

You can buy a humidifier here at many sources. Enter the words “oxygen humidifier” into any internet search engine to find suppliers. Here is one:

Mountainside Medical Equipment:

[www.mountainside-medical.com/search.php?search\\_query=oxygen+humidifier&x=65&y=11](http://www.mountainside-medical.com/search.php?search_query=oxygen+humidifier&x=65&y=11)

## Portable Oxygen System

A document created by OUCH (the Organization for Understanding Cluster Headaches) describes a backpack-size portable oxygen system, as follows (figures 1-3 are also from the OUCH document):

There are backpack assemblies you can use at home and take to work. Integrated backpack O<sub>2</sub> delivery systems, like the unit shown below [Figures 1 and 2], provide nearly 3 hours continual use at a flow rate of 10 liters/minute. It is also configured with a “bubbler” humidifier illustrated in the photo on the left. As indicated earlier in the section on humidifiers, a bubbler adds enough moisture to the normally dry O<sub>2</sub> to prevent dryness in the mouth and upper breathing passages.

There are also smaller portable O<sub>2</sub> kits with backpacks that CHers can use to gain even more mobility. The portable O<sub>2</sub> kit shown below in Figure 3 comes equipped with three 1-liter bottles of compressed O<sub>2</sub> charged to 3000 psi (200 BAR), a constant flow regulator, NRB mask, tubing, and the backpack. Depending on flow rate, each bottle holds 200 liters of O<sub>2</sub> that can be used to abort from one to three CH attacks.[7](#)



Figure 1



Figure 2



Figure 3

Laws that govern carrying or using portable O<sub>2</sub> cylinders while traveling by public ground transportation or airlines vary greatly.

### **10. Thoughts about Talking to Your Doctor**

*Oxygen can change your life, or even save it—you cannot let yourself be at the mercy of a doctor who doesn't know that, or doesn't seem to care.*

As noted above, many doctors are unaware of the effectiveness of oxygen for aborting CH attacks. Here are four suggestions in that regard.

First, get the studies about O<sub>2</sub> to your doctor, preferably in advance of your appointment so s/he might have time to look them over. If you can't do that, then print them out and bring them to your appointment. Here they are again:

Rozen, T., and Fishman, S. "Inhaled Oxygen and Cluster Headache Sufferers in the United States: Use, Efficacy and Economics: Results From the United States Cluster Headache Survey" *Headache* (2010) at

<http://www.clusterheadaches.com/O2/Oxygen-survey-final.pdf>

Cohen, A., Burns, B., and Goadsby, P. "High-Flow Oxygen for Treatment of Cluster Headache." *Journal of the American Medical Association* (2009). at <http://jama.ama-assn.org/content/302/22/2451.full>



Experience suggests that the doctor is not likely to actually read them, but you can try—and in any event, you have opened the door to discussing them.

Second, read the articles yourself, make some notes, and be prepared to make your case. Don't count on your doctor having read them.

Third, consider having someone come with you to your appointment. We all have had those times when we really didn't get satisfactory service from a physician and later regretted it. Especially if you're already feeling crummy, someone with you as an advocate can help a lot. (And, if you're worried about alienating your doctor, that other person can be assertive without you having to risk alienating the doc.)

Fourth, you might have to help your doctor write your prescription. So know what you want: two or more big tanks, a smaller one or two for local travel or the office; *at least* a 15 lpm regulator for each type of tank (try for a higher-flow regulator); and a non-rebreather mask. . Your doctor should write "As needed for cluster headaches" on the prescription.

Remember, getting the prescription for the tanks is the most critical thing, because you can purchase a regulator and a mask for yourself if you have to. And remember also—a [concentrator](#) will be nearly useless to you.

Often a doctor will just write a prescription for O2 without specifying much more. It's important for you to follow up with your oxygen supplier so you know you'll be getting what you need

If you do not get O2 from your doctor and no satisfactory reason is provided to you, seriously consider firing your doctor and finding another one. Call around. Try to find a neurologist who has experience with cluster headaches, or at least a headache specialist or headache clinic. This will increase your odds of getting a prescription for oxygen.

OUCH (the Organization for Understanding Cluster Headaches) provides lists of doctors in the US, Canada, and internationally who have been recommended by CH sufferers; presumably those docs are more aware of the benefits of oxygen and more willing to prescribe it. You can find those lists here: <http://www.ouch-us.org/chgeneral/doctors.htm>

To repeat what we said at the beginning of this section: *Oxygen can change your life, or even save it—you cannot let yourself be at the mercy of a doctor who doesn't know that, or doesn't care.*

## **11. Working with Your Oxygen Supplier**

For many people, relationships with oxygen suppliers are very positive. In other cases, an oxygen supplier might not know much about cluster headaches or the equipment required to treat them. If you find that your supplier lacks knowledge, consider emailing, faxing, or otherwise providing the [key articles about oxygen and CH](#) to them.

You should call your oxygen supplier as soon as possible after receiving your prescription, to be sure the supplier understands what you need.

You should be sure that your O2 provider sets up your tank, regulator, and mask, shows you how to use them, and covers the necessary safety precautions. It's all quite simple, but you don't want to be figuring anything out for yourself that others could be telling you.

## **12. Some Sources for Supplies**

[A note about links: We have tried throughout this document to insure that links are current and functional. However, things change.]

### Regulators

Many people order a regulator from eBay. Go to [www.ebay.com](http://www.ebay.com) and type [oxygen regulator] (without the brackets) into the search window. Here's a link:

<http://www.ebay.com/sch/i.html?from=R40&trksid=p5197.m570.1311&nkw=medical+oxygen+regulator&sacat=See-All-Categories>

Many internet suppliers also sell regulators. Here are some examples. The first three sell regulators of 25 lpm or more, as well as 15 lpm regulators.

Linde Healthcare

[http://www.lifegas.com/gas\\_devices\\_and\\_therapies/special\\_oxygen\\_needs.asp](http://www.lifegas.com/gas_devices_and_therapies/special_oxygen_needs.asp)

Mada Medical

<http://madamedical.com/>

Flotec Respiratory Products

[http://www.floteco2.com/htm/Products/Regulator/Regulator\\_RW\\_100-300\\_Catalog\\_Imag...](http://www.floteco2.com/htm/Products/Regulator/Regulator_RW_100-300_Catalog_Imag...)

Tina's Homecare

[http://www.tinashomecare.com/oxygen\\_therapy\\_oxygen\\_regulators.htm?gclid=CMP24tOb...](http://www.tinashomecare.com/oxygen_therapy_oxygen_regulators.htm?gclid=CMP24tOb...)

## Masks

You can order an O2ptimask at

<http://www.clusterheadaches.com/khxc/>

In Europe, you can order the O2ptimask at

<http://headachemasters.com/product.asp?product=3>

You can order non-rebreather masks through eBay. Go to

[www.ebay.com](http://www.ebay.com) and type [non-rebreather mask] (without the brackets) into the search engine. This link should work:

[http://www.ebay.com/sch/i.html?\\_from=R40&\\_trksid=m570.12736&\\_nkw=non-rebreather+mask](http://www.ebay.com/sch/i.html?_from=R40&_trksid=m570.12736&_nkw=non-rebreather+mask)

You can find standard non-rebreather masks at many internet locations. Enter the words "non-rebreather mask" into a search engine to find suppliers. Note that these masks are quite inexpensive, so if you see a price quoted of more than a couple of dollars, it is probably for a case of masks, not just for one.

## Demand Valve:

You can see demand valve systems at places that include those below. You probably will need support from an oxygen supplier to obtain such a system (sometimes they are available for sale on eBay).

Linde Healthcare

[http://94.100.244.217/gas\\_devices\\_and\\_therapies/regulators%20and%20demand%20valves.asp](http://94.100.244.217/gas_devices_and_therapies/regulators%20and%20demand%20valves.asp)

BPR Medical (UK):

[www.bprmedical.com/ultraflow/oxygen-demand-valve](http://www.bprmedical.com/ultraflow/oxygen-demand-valve)

## Oxygen Cylinder Stand/Cart

Tina's Homecare:

[http://www.tinashomecare.com/oxygen\\_cylinder\\_stands.htm](http://www.tinashomecare.com/oxygen_cylinder_stands.htm)

Medical Supply Depot:

<http://www.medicalsupplydepot.com/Respiratory/Oxygen-Cylinder-Carts/?gclid=CIK3tN2E6rACFYcBQAodhW9g2A>

### Humidifier/”Bubbler”

Enter the words “oxygen humidifier” into any search engine to find suppliers. You can buy one here, as well as at many other locations: [www.mountainside-medical.com/search.php?search\\_query=oxygen+humidifier&x=65&y=11](http://www.mountainside-medical.com/search.php?search_query=oxygen+humidifier&x=65&y=11)

### Longer Tubing

Many people like to use longer tubing, so that they can pace while using O<sub>2</sub>. You can purchase longer tubing, or adapters to extend additional tubing. To find sources, enter the words [oxygen tubing] (without the brackets) into an internet search engine. Here is one internet site that has a 25-foot tube: <http://www.mountainside-medical.com/products/Dynarex-Oxygen-Tubing-25-%27-Lumen-No-Crush-Tubing.html>

## **13. If You Run Out of Oxygen**

Some people with CH suggest that if your tanks become empty and you can't get your supplier to fill them on time, or if you do not yet have any oxygen setup, you could try going to your local fire station, where there might be emergency medical technicians (EMTs) who are trained in giving oxygen. The “oxygen page” at clusterheadaches.com says, “They are often willing to help you more than if you went to the Emergency Room and had to deal with staff that may be ignorant of oxygen therapy for cluster headache.”<sup>8</sup> The Emergency Room is another option, though.

## **14. Oxygen and Travel**

You cannot bring an oxygen tank onto an airplane without advance arrangements, if at all. Check with your airline first and inquire about their policy. If they do provide oxygen find out what it is going to cost, what flow rate they have available, what quantity/volume they can provide, and whether you can use your own mask. There are reports of people arranging for oxygen onboard a plane only to discover they had a maximum flow rate of 3 lpm thorough nasal cannula. Check first and allow plenty of lead time.

Some suppliers will work with you to have oxygen available in places you are traveling to. See, for example, the “Oxytravel” service at Linde Healthcare: [http://www.linde-healthcare.com/en/about\\_linde\\_healthcare/Patient-focused\\_care/oxytravel/index.html](http://www.linde-healthcare.com/en/about_linde_healthcare/Patient-focused_care/oxytravel/index.html)

## 15. About Welding Oxygen

A study reported that about 12 percent of people with CH who use oxygen to treat their attacks use “non-medical welding grade oxygen,” adding that such oxygen “could be harmful to the user depending on the gas or gases the cylinder was previously filled with and trace gases still present in the cylinder.”<sup>9</sup> People who use welding oxygen do so for a variety of reasons—doctors who won’t prescribe O<sub>2</sub>, for example, or insurance issues.

Please understand that we DO NOT recommend using anything other than prescribed medical oxygen provided by an approved vendor. Yes, that is the disclaimer.

Those who use welding oxygen acquire their other equipment—regulator, mask, etc.—from sources described in this document, [here](#). (Most outlets that sell or rent cylinders for welding oxygen also sell regulators. The regulator will not have a liters-per-minute reading, but it can be adjusted just by opening the valve so the reservoir bag on the mask fills readily.)

Medical oxygen obtained by a doctor’s prescription is strongly preferred as the way to abort cluster headaches. See the section, “[Thoughts about Talking to Your Doctor](#).” When that way is not feasible, welding oxygen might be a valuable alternative should you chose to disregard the disclaimer above.

You can read many discussions about welding oxygen at the websites [www.clusterheadaches.com](http://www.clusterheadaches.com) and [www.clusterbusters.com](http://www.clusterbusters.com), by going to the discussion boards at those sites and typing the word **welding** into the search bar on the top left side of the page.

Note that SCUBA tanks are not appropriate under any circumstances for treating cluster headaches: they contain compressed air, not pure O<sub>2</sub>.

## 16. Web Resources

Oxygen use is a frequent topic at the message boards of [www.clusterheadaches.com](http://www.clusterheadaches.com) and [www.clusterbusters.com](http://www.clusterbusters.com). If you enter a key word or phrase—such as *demand valve* or *welding*—into the search engine at the top left of any page of those message boards, you will be led to many helpful conversations. Or, of course, you can ask your own questions in the forums. You are certain to receive helpful, supportive advice.

## **Addendum: Increasing the Effectiveness of Oxygen**

For some people with CH, conventional oxygen therapy can gradually decline in effectiveness, until they feel that oxygen no longer really works satisfactorily for them as an abortive. Some others report that oxygen therapy has never worked for them. While it is true that in a small number of cases oxygen therapy is for some reason ineffectual, many people have experienced good results with equipment and methods that go beyond the conventional ones. Here are some suggestions in that regard.

*For sources to purchase any of the items described below, see Section 12, page 18.*

Higher flow rates. If you are using a non-rebreather mask or other breathing device (such as a breathing tube) that has a reservoir bag, you can only take in O<sub>2</sub> as fast as the bag refills after each inhalation. Since rapid deep breaths, or even hyperventilation, are the preferred breathing techniques (see more discussion of this below), a flow of 15 liters per minute [lpm] often is not enough to provide a ready supply of O<sub>2</sub> in the reservoir bag for each inhalation. Many people with CH are finding that higher flow rates, of 25 lpm and more, insure that they do not have to wait between inhalations.

Although we cannot recommend this, many people with 15 lpm regulators get good results from replacing the reservoir bag on their mask with an unscented garbage bag or turkey bag.

Demand Valve System. With a demand valve system, you never have to wait for a reservoir bag to fill. O<sub>2</sub> is immediately available as long as there is O<sub>2</sub> in your tank. A demand valve system requires a certain type of regulator—one with a DISS fitting that bypasses the lpm setting on the regulator—so you must be sure you have the correct parts, and a demand valve can be costly at \$350 or more, but many have benefitted from them when other systems have not worked to abort their attacks. Your oxygen supplier, or a person at a facility that sells demand valves, can help you obtain the right equipment.

Here is a photo of a demand valve mask connected to a regulator by a high-pressure hose.



O2ptimask. The O2ptimask is designed to replace the typical non-rebreather mask on a conventional (non-demand-valve) O2 setup. It was designed specifically for people with CH, to get as much O2 inhaled as possible, as quickly as possible. It forms a strong seal with the face (and comes in different sizes to accommodate different face sizes); it has no vent holes with “flapper valves”; the reservoir bag is much larger than on a conventional non-rebreather mask; and it is very durable. Many people with CH say that it aborts an attack in about half the time as a standard non-rebreather mask, particularly when used with a regulator with a flow of 25 lpm or more.

Breathing Strategies. It is always valuable to get as much O2 as possible into your lungs, and to remove as much room air as possible from your lungs. People with CH use many strategies to accomplish that, and you should try different methods to find what works best for you. There are many discussions of breathing strategies on the message boards at [www.clusterheadaches.com](http://www.clusterheadaches.com), and you can find them by typing an appropriate key word such as *breathe*, *inhale*, or *hyperventilate* into the search engine there. With a 15 lpm regulator, the breathing strategy will typically involve breathing more rapidly and more deeply than your normal breathing, and being sure to exhale fully each time. Your respiration rate should be 24-30 in/out breath cycles per minute, whereas a typical “normal” respiration rate is between 12 and 20 cycles per minute. (Most people with CH find it difficult to count their respiration cycles while they’re trying to abort an attack, so these numbers are more to give you an idea of the difference between “normal” respiration rates and how you might breathe in O2.)

Some suggest breathing in through the nose if possible (if you’re not too congested), and out through the mouth. You might try this to see whether it improves your success at aborting your attacks.

At flow rates of 25 lpm and higher, or with a demand valve, it may be feasible for you to breathe more assertively, forcibly exhaling as much air as possible from the lungs and inhaling as fully as possible. A “hyperventilation” method has been used with success by some people. To read more about that method, enter the word *hyperventilate* into the search engine at the message board at [www.clusterheadaches.com](http://www.clusterheadaches.com). Here is a link to one entry (we cannot guarantee that the link will always be operative, but it was at the time this paper was published): See particularly the fifth entry, by “Batch,” on this page: <http://www.clusterheadaches.com/cgi-bin/yabb2/YaBB.pl?num=1313766756>

CAUTION should be used with hyperventilation and any of the breathing strategies described here, if you choose to try them.

Energy Drinks. Many people with CH report that they abort their attacks more rapidly when they quickly drink an “energy drink”—such as RedBull, Monster, or 5-Hour Energy, containing caffeine and taurine—at the first sign of a CH attack, followed by immediately using O<sub>2</sub>. Caffeine alone (in a strong cup of coffee, for example) can also help.

## **ENDNOTES**

*[The links in these endnotes were working when the document was created. We apologize for any that have subsequently become broken.]*

*Also, we wish to thank Clusterheadaches.com and DJ for his kind permission to use many of the pictures and some of the content from his web site in the preparation of this article. For additional information, please see those pages at:*

*<http://www.clusterheadaches.com/O2/index.html>*

- 1 Rozen, T., and Fishman, S. “Inhaled Oxygen and Cluster Headache Sufferers in the United States: Use, Efficacy and Economics: Results From the United States Cluster Headache Survey” *Headache* (2010) at <http://www.clusterheadaches.com/O2/Oxygen-survey-final.pdf> [GO BACK]
- 2 Rozen, T., and Fishman, S. “Inhaled Oxygen and Cluster Headache Sufferers in the United States: Use, Efficacy and Economics: Results From the United States Cluster Headache Survey” *Headache* (2010) at



- <http://www.clusterheadaches.com/O2/Oxygen-survey-final.pdf> [GO BACK]
- 3 Cohen, A., Burns, B., and Goadsby, P. “High-Flow Oxygen for Treatment of Cluster Headache.” *Journal of the American Medical Association* (2009). At <http://jama.jamanetwork.com/article.aspx?articleid=185035> [GO BACK]
  - 4 Agency for Healthcare Research and Quality. “Guidelines: Cluster Headache and Other Trigemino-Autonomic Cephalgias.” (2011) At <http://www.guidelines.gov/content.aspx?id=10471> [GO BACK]
  - 5 Cohen, A., Burns, B., and Goadsby, P. “High-Flow Oxygen for Treatment of Cluster Headache.” *Journal of the American Medical Association* (2009). At <http://jama.jamanetwork.com/article.aspx?articleid=185035> [GO BACK]
  - 6 Kahn, B., Do, A., Berger, M., Thørn, S., and Batcheller, P. “A Cluster Headache Sufferer’s Supplemental Guide to Aborting Cluster Headache Attacks with 100% O2” page 21 at [http://www.ouch-us.org/medications/oxygen/O2\\_CH\\_Abortive\\_v2r7\\_Final.pdf](http://www.ouch-us.org/medications/oxygen/O2_CH_Abortive_v2r7_Final.pdf) [GO BACK]
  - 7 Kahn, B., Do, A., Berger, M., Thørn, S., and Batcheller, P. “A Cluster Headache Sufferer’s Supplemental Guide to Aborting Cluster Headache Attacks with 100% O2” Pages 24-25 at [http://www.ouch-us.org/medications/oxygen/O2\\_CH\\_Abortive\\_v2r7\\_Final.pdf](http://www.ouch-us.org/medications/oxygen/O2_CH_Abortive_v2r7_Final.pdf) [GO BACK]
  - 8 See <http://www.clusterheadaches.com/O2/index.html> [GO BACK]
  - 9 Rozen, T., and Fishman, S. “Inhaled Oxygen and Cluster Headache Sufferers in the United States: Use, Efficacy and Economics: Results From the United States Cluster Headache Survey” *Headache* (2010) at <http://www.clusterheadaches.com/O2/Oxygen-survey-final.pdf> [GO BACK]