



Patient Guide

CMS Open Comment Period on Home Use of Oxygen and Home Oxygen Use to Treat Cluster Headaches (CAG-00296R2)

[CMS Guidelines for Submitting Patient Comments](#)

Tips for Patient Submission

- Start a Word or Google document to draft your letter. You will have to copy and paste your letter into a comment box and you'll want to have a copy of the letter for your records too.
- According to CMS, "Public comments that are part of letter writing campaigns by groups or individuals who espouse a single point of view through identical or nearly identically worded emails or documents are not useful. Multiple iterations such as these will be considered as a single comment." CMS will not accept form letters or fill-in-the-blank type letters.
- Try to be succinct, yet vivid. Aim for 300 or less words
- All comments will be published to the [CMS website](#), so please only share what you are comfortable with being published online. CMS may also redact any personally identifiable information included in your submission.
- **We cannot provide a template letter for you to fill in, only provide guidance. The following are suggestions on what to include in your comments that will capture the attention and provide detail CMS needs in order to make a determination. Choose the highlight the pieces that resonate with you most and help CMS understand, if applicable, how the denial of Oxygen has caused you harm.**

Introduction

Include where you live and your age (especially if you are 65 or over) and your diagnosis. (episodic or chronic? Any other headache disorder?)

How old were you when you had your first cluster attack?

How long did it take to receive a proper diagnosis of cluster headache?

How many cycles do you experience in a year, how long do they last and how many attacks do you have per day?

If you are chronic, on a typical day, how many attacks do you have?

Explain in vivid detail what a cluster attack feels like.

Suicide and Cluster

During an attack, have you ever considered or contemplated suicide?

Have you ever attempted suicide?

Health Insurance Coverage

What type of health insurance do you have? Through your employer, through the Affordable Care Act or Medicare/Medicaid? Are you currently receiving Medicare benefits because you are retired?

Are you under the age of 65 and receiving Social Security Disability benefits due to the debilitating effects of living with cluster?

Have you ever been prescribed oxygen by a health care provider and not been able to obtain approval from your insurance company? Did the denial letter state the reason why? If so, share those reasons. Was this your current health insurance company, Medicare/Medicaid or was the denial from a different carrier?

Treatments

How many different therapies have you tried to abort cluster attacks? Include pharmaceuticals, medical devices, supplements, vitamins and any other substance. Share only what you are comfortable with being publicly available online.

How ineffective are these treatments? What side effects have you experienced from these treatments? Are you unable to treat all of your attacks due to safety limitations?

Have you ever been prescribed opioids to treat your cluster attacks?

How much do you spend each year to manage your disease? Include all medical, insurance premiums, cost of oxygen, copays, deductibles, medications, complementary alternative methods, etc. that relate to cluster headache. If you don't have this information, it's ok to skip it.

Have you been limited in your access to oxygen? If so, what did that look like for you? Did you use welders oxygen instead? Did you go without and suffer more greatly? Did you go to the ER only to get there and have the attack complete before you could be treated?

Call for Access to Oxygen

Call on CMS to appropriately honor your pain and approve the coverage of high flow oxygen. Demand that CMS, and private insurance companies that determine their policies based on the policies of CMS, support those living with cluster headache disease so they can live healthier, better and longer lives. We shouldn't lose one more person to this disease because they are denied access to high-flow oxygen.

If you feel comfortable, please send a copy of your submission to info@allianceforheadacheadvocacy.org. If you choose to send us your submission, you are providing consent for Alliance for Headache Disorders Advocacy and any partner organizations to use non-personally identifiable information stated in your comments.

YOUR VOICE TRULY MATTERS – THANK YOU FOR SHARING YOUR STORY

[Click here to submit your public comments](#)