



Caregiver 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 Caregiver 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 more 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. **DO NOT STATE THE NAME OF THE PATIENT IN YOUR COMMENTS - INSTEAD REFER TO THE PERSON AS "PATIENT or PERSON LIVING WITH CLUSTER DISEASE."**
- **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 your loved one harm.**

Introduction

Include where you live. State your relationship to the patient you are a caregiver for (spouse, partner, family member, friend, coworker, member of the health care community.)

What is the diagnosis of the patient? (episodic or chronic? Any other headache disorder in addition to Cluster?)

Do you know when the patient experienced his/her first cluster attack?

Do you know how long it took to receive a proper diagnosis of cluster headache?

Discuss what you know about the patient's cycle of attacks - how many cycles are experienced in a year, how long does a cycle last, and how many attacks are averaged in per day?

If the patient is chronic, on a typical day, how many attacks does he/she have in a day?

Many patients do not want others to witness a cluster attack. Have you ever witnessed or been in close proximity to a patient during a cluster attack? Explain in vivid detail the actions, sounds, mental state, the pain you witnessed.

Suicide and Cluster

Has the patient ever discussed thoughts of suicide or attempted to die by suicide?

Health Insurance Coverage

What type of health insurance does the patient have? Through the employer, through the Affordable Care Act or Medicare/Medicaid? Who is his/her insurance carrier? What state does the patient live in?

Is the patient currently receiving Medicare benefits because he/she is retired?

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

Oxygen

Has the patient ever been prescribed high-flow oxygen by a health care provider? Was it approved by the insurance carrier?

Was the prescription claim denied by insurance. 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?

At any point has the patient had access to high-flow oxygen? If yes, how did use of high-flow oxygen change the duration and severity of an attack? Are you aware of any side effects?

Since using high-flow oxygen to manage his/her cluster disease, has there ever been an instance where the patient did not have a tank available? How did the experience of this attack differ then one treated with oxygen?

How much does the patient spend each year to manage his/her cluster 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.*

Has the patient ever been limited in your access to oxygen? If so, what did that look like? Did he/she use welders oxygen instead? Did he/she 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 loved one's 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](#)