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## Comment Submission Guide

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

#### Tips for [Comment Submission](#)

- Start a Word or Google document to draft your letter/comments. You will have to copy and paste your letter/comments into a comment box and you'll want to have a copy 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 to highlight the pieces that resonate with you most and help CMS understand, if applicable, why home use oxygen needs to be approved for ALL Medicare beneficiaries with cluster headache (CH).

#### AHDA Assessment

While there is progress indicated by the new [Proposed Decision Memo](#), there are still items that AHDA feels need to be changed before the policy is finalized.

- All Medicare patients with a CH diagnosis should be eligible for insurance covered home-use oxygen.
- The coverage determination should be made at the CMS / National level and not moved down to the individual Medicare Administrative Contractors (MAC).

- Clarification is needed as to whether blood gas studies would be required prior to approval of home use oxygen for CH.

AHDA is appreciative and supportive of the following proposed changes.

- Home use oxygen for CH now being a coverable treatment.
- Removal of the Certificate of Medical Necessity (CMN) requirement
- Removal of a fail first requirement (e.g. recognition that oxygen itself may be “optimum therapy”)
- Removal of “chronic stable state” language as this does not apply to CH which occurs in bouts of relatively short duration.

## **Suggested prompts for drafting your comments/feedback**

### **Introduction**

How long have you been living with cluster headache or treating patients with 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?

When you are in cycle, how many attacks do you have per day typically?

### **Treatments**

*Our goal is to capture comments/testimonials from people who can explain that the recommendation to get oxygen in an Emergency Department (ED) or providers office is NOT helpful or effective. CMS needs to better understand why **home use Oxygen** is so necessary.*

Have you ever gone to an Emergency room or a provider’s office to receive oxygen as a way to abort an attack? 99% of you will probably say no. Please tell CMS that this is the case and explain why you do not get your oxygen in these settings (e.g. you can’t get into the ED or provider’s office in time for the attack to be treated; you have attacks multiple times day; you are unable to drive during an attack; your attacks are in the middle of the night, etc.)

Have you ever gone to the ED to get oxygen but they didn’t understand the protocol you needed and gave you something different instead? Explain how painful and unacceptable this was.

Have you tried other treatments beside oxygen to abort your cluster headache attacks that was less effective than O2? If so, what have you tried and why was oxygen the better option for you.

## **Health Outcomes**

*CMS places greater emphasis on health outcomes actually experienced by patients. If applicable, please comment with specific examples of how the use of home oxygen has:*

Improved your quality of life

Improved your ability to function / functional status

Reduced the duration of your attacks and impact on your disability

## **Health Care Provider Perspective:**

*It would be helpful for providers to focus on the importance of writing the policy in a way the it covers ANY patient who has received a medical diagnosis of CH. The current proposal speaks of “select patients” which leaves too much ambiguity regarding who will be covered and who will not.*

Have you ever encouraged a patient to come into your clinic or go to the emergency room to receive oxygen for an active cluster headache attack? If not, please explain why this is not a reasonable solution for a patient.

Do you believe a diagnosis from a provider of cluster headache should be all that is required for a home-use oxygen prescription to be approved? Or do you feel there are certain patients that should be covered and others that should not? Please explain.

## **Call for Access to Oxygen**

Call on CMS to appropriately honor your pain and finalize the Proposed Decision Memo, with revisions, to allow ALL Medicare patients with a diagnosis of cluster headache to have access to home-use oxygen.

YOUR VOICE TRULY MATTERS – THANK YOU FOR SHARING YOUR STORY

**[Click here to submit your public comments before Aug 1](#)**