

CLUSTER HEADACHE

GENERAL INFORMATION:

What are cluster headaches? Cluster headaches are a chronic (long-term) condition that causes very bad, sometimes unbearable head pain. The headaches happen in "clusters" or groups. The headaches may happen one or more times a day over a period of weeks or months. Each headache can last from 30 minutes to several hours. At the end of the cluster cycle, the headaches suddenly stop. They usually do not come back for six months to a year, or even longer. The periods of time where you do not have cluster headaches are called remissions (ree-MISH-uns). Rarely, cluster headaches can happen for a year or more without a remission.

Why do cluster headaches happen?

- **Who gets them:** Scientists do not know why some people get cluster headaches and others do not. The first cluster headache a person has usually happens between the ages of 20 to 40 years old. People with cluster headaches sometimes have a history of migraine headaches. You are more likely to have cluster headaches if you are male. Smoking or drinking alcohol increases your chance of having cluster headaches.
- **What causes them:** Scientists do not know for sure what causes cluster headaches. They may be caused by blood vessels or nerves in the head not working as they should. Ask your caregiver for the most up-to-date information about what may cause cluster headaches.
- **Things that may trigger (start) them:** Cluster headaches happen more often during the spring or fall, when the amount of daily sunlight changes. Glare from sunshine or lights, drinking alcohol, smoking, and certain foods may trigger them. Napping in the daytime may cause a cluster headache also. Some medicines, such as nitroglycerin ("nitro"), may cause a cluster headache.

Are there warning signs before a cluster headache starts? In most people, cluster headaches happen suddenly and without warning. However, some people get signs before the pain of a cluster headache starts. Warning signs of a cluster headache may include:

- Being bothered more than usual by bright light, smells, or loud noise.
- Nausea (upset stomach), or vomiting (throwing up).
- Visual changes, often called **auras**, which may include:
 - Blind spots that last for a short time.
 - Seeing bright spots, lines, or other things that are not there (hallucinations).
 - Your vision may blur, or things may look different.

What are the symptoms of a cluster headache? An active period of cluster headaches usually lasts for six weeks to two months or more. During an active period, the headaches can happen one or more times a day. They often come back at the same time each day. They sometimes happen at night, with pain that wakes you from sleep.

- **How the pain begins:** Cluster headaches start with sudden, intense pain on one side of the head. The pain usually starts in or around one eye and spreads to the same side of the head. The pain may also spread to one side of your face, anywhere from your neck to your forehead. You may even have pain in your teeth, jaw, neck, or shoulders. The pain quickly grows to its worst within five or ten minutes after the headache starts. The pain of a cluster headache can be sharp, burning, or piercing. It usually lasts from 30 minutes to two hours, but may last longer.
- **Other symptoms you may have:** You may have red or watery eyes and a runny or congested (stuffy) nose. You may also have swelling of one or both eyelids. These symptoms may happen only on the same side of your head as the headache. Some people have a smaller than normal pupil (black center of eye) or droopy eyelid on that side also.

This is called Horner (HOR-ner) syndrome. The eyelid and pupil usually return to normal after the headache is gone. You may become flushed (turn red) on one or both sides of your face. You may feel restless, like you need to pace the floor or rock in a chair. You may be bothered more than usual by light, sound, or smells. You may get sick to your stomach.

How are cluster headaches diagnosed? Your caregiver will examine you and ask you questions. You may have blood taken for tests. A neurologic (nu-roh-LAH-jik) exam to check your brain and nerves may be done also. You may need other tests to make sure your symptoms are not caused by a more serious problem. You may need one or more head scans, such as an MRI or a CT scan. Different scans can help your caregivers check for problems with the tissue and blood vessels of your head. Ask your caregiver for more information about tests you may need.

How are cluster headaches prevented and treated? There is no cure for cluster headaches, but with treatment they may be controlled. Ask your caregiver for the most up-to-date treatments for cluster headaches. The following are some things that may decrease the number of headaches you have or how long they last.

- **Avoid smoke, and avoid drinks that contain alcohol:** It is never too late to quit smoking. Besides causing cluster headaches, smoking increases your chance of having a heart attack, lung disease, and cancer. Alcohol may also cause your cluster headaches. Alcohol reacts badly with many of the medicines used to treat cluster headaches. Avoid alcohol, especially during an active period of cluster headaches.
- **Find and avoid triggers:** Use a diary or calendar to keep track of your cluster headaches. Write down when your headaches start and stop, what you were doing when they started, and your symptoms. Record anything you ate or drank during the 24 hours before the headaches started. Describe how the pain feels, where it is, and how bad it is. Keep track of the things you did to help your headaches and when you did them. Record whether these things helped your symptoms or not. This record will help you learn what may trigger your headaches and what helps them the most. Bring this diary with you every time you see your caregiver.
- **Medicines:** You may need to try a lot of different medicines before you find the ones that help you. Sometimes medicines that were helpful in the past may stop working. Work closely with your caregiver when you need to change your medicines. Some medicines used to treat cluster headaches may have side effects. Ask your caregiver for more information about the medicines you are taking. The two most common types of medicine used for cluster headaches include the following.
 - **Preventive medicines:** Medicines that are taken every day during an active period of cluster headaches are called preventive (pree-VEN-tiv) medicines. Preventive medicines may help decrease the number of headaches you have during the active period of cluster headaches. You may only need to take preventive medicines for a few weeks or months. Your caregiver may stop the medicines after the period of cluster headaches has passed. Preventive medicines often need to be tapered off (stopped slowly) when the period of cluster headaches is over. You may not need them again until the next time your headaches come back.
 - **Fast-acting medicines:**
 - Fast-acting medicines may help decrease or stop the pain of a cluster headache once it starts. Some fast-acting medicines are given as a shot (with a needle). Some are given as a suppository (su-POZ-i-tohr-ee) that goes in the rectum (rear end). Some may be given other ways, such as under the tongue or in the nose. Fast-acting medicines are given in these ways so they can get into your bloodstream quickly. They start to work faster than most pills do. It is important to take your fast-acting medicine at the first sign of a cluster headache.

- Over-the-counter pills usually do not help a cluster headache. This is because the headache may be gone by the time these medicines start to work.
- **Oxygen:** Some people are helped by breathing extra oxygen during a cluster headache. You get the extra oxygen by breathing through a special plastic mask that is attached to an oxygen tank. It is only used for a few minutes, and only during a cluster headache. Your caregiver will tell you how you should use oxygen if you need it to treat your headaches.
- **Special care:** If you are having trouble controlling your cluster headaches, you may need to see a special caregiver. Some caregivers, such as neurologists (nu-ROL-oh-jists) or those at pain clinics, specialize in treating cluster headaches. Rarely, a person with severe (very bad) symptoms that are not helped by medicine may need surgery.

Can cluster headaches cause other serious health problems?

- Cluster headaches are usually not the cause of other serious health problems. You may have side effects from certain medications used to treat your cluster headaches. Because of the severe pain they cause, cluster headaches may decrease the quality of your life. Some people have anxiety (worry) or depression (sadness) because of their pain. People who have frequent cluster headaches may sometimes have thoughts of ending their life. If you have thoughts of hurting yourself, tell a caregiver right away.
- Some people who have cluster headaches are at an increased risk of getting permanent Horner syndrome. Horner syndrome is having a droopy eyelid or small pupil in one eye. These symptoms may happen during a cluster headache, but usually go away when the headache stops. Over time these symptoms may stay, even between headaches.

For support or more information: Some people find it helpful to talk with others who are also living with cluster headaches. Support groups and national organizations can help you learn more about cluster headaches. Ask your caregiver for a support group in your area, or contact the following organizations:

- National Headache Foundation
820 N. Orleans, Suite 217
Chicago, IL 60610
Phone: 1-888-NHF-5552
Web Address: <http://www.headaches.org>
- National Institute of Neurological Disorders and Stroke
National Institute of Neurological Disorders and Stroke
P.O. Box 5801
Bethesda, MD 20824
Phone: 1-800-352-9424
Web Address: <http://www.ninds.nih.gov>

CARE AGREEMENT:

You have the right to help plan your care. To help with this plan, you must learn about your health condition and how it may be treated. You can then discuss treatment options with your caregivers. Work with them to decide what care may be used to treat you. You always have the right to refuse treatment.

The above information is an educational aid only. It is not intended as medical advice for individual conditions or treatments. Talk to your doctor, nurse or pharmacist before following any medical regimen to see if it is safe and effective for you.

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