



Topic **Chronic Cluster Headache**

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Title & Organization

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## KEY TAKEAWAYS

- Cluster headache and migraine share many clinical features.
- Cluster headache is a “side-locked” headache disorder: It always happens on the same side.
- Cluster headache attacks are brief and can happen many times a day, including overnight.
- Increased activity and restlessness are characteristic of cluster headache attacks. Symptoms can include blinding pain, a red eye, runny nose, stuffiness, and fullness in the ear.
- Cluster headache is sometimes misdiagnosed as a sinus or dental problem.
- On a pain scale, people around the world rank cluster headache as a 9.5/10, which is higher than the pain of a gunshot wound, kidney stones, birth, migraine, and pancreatitis.
- Episodic cluster headache means having one or more attacks per day for weeks/months at a time, with a period of relief lasting months to years.
- Chronic cluster headache means having cluster attacks for at least nine months out of the year.
- Cluster headache has timing features: Attacks tend to happen at the same time of day and/or year for a given patient.
- Smoking and sleep apnea are both associated with cluster headache.

## QUOTES

“Over time we have seen that the proportion of cluster diagnoses in men and women has actually gotten closer together, as there’s been better recognition that — if you ask the questions the right way — there are plenty of women who have this problem.”

“We can now state definitively that cluster headache is the most painful condition known to human beings.”

“The main difference about chronic cluster is a matter of degree. By definition, chronic cluster means once you’ve become a chronic cluster patient, you are in that corner, most of the time, for the foreseeable future. And that is — both in terms of function, but also in terms of the psychological and emotional burden — a huge difference.”

“Things have gotten so much better in my lifetime of treating headache disorders ... from the fact that the delay in diagnosis has been cut by almost 75%, to the fact that we now have multiple approved treatments; that there is ongoing research, that the recognition of, the awareness of, this disorder is growing all the time.”

## TREATMENTS CITED

- |                            |                        |
|----------------------------|------------------------|
| Beta blockers              | Oxygen                 |
| CGRP monoclonal antibodies | Psilocybin             |
| CGRP oral treatments       | Steroids               |
| Depakote                   | Sumatriptan injections |
| Eptinezumab (Vyepi)        | Topamax                |
| Lithium                    | Vagal nerve stimulator |
| Nasal sprays               | Verapamil              |
| Nerve blocks               | Zolmitriptan nasal     |
|                            | sprays                 |

## PRACTICAL STEPS

- Talk to a certified headache specialist to find both acute and preventive treatments that work for you.
- Consider trying some of the nonmedication options that work for migraine.
- Join an organization like Clusterbusters or Headache on the Hill to advocate for more research on and better availability of treatments on the regional and national levels.