

**INSTRUCTIONS:**

The information you enter in this diary will help to develop better ways to treat and study cluster headache, should you share your diary or even just your experience using this diary with Clusterbusters ([www.clusterbusters.com](http://www.clusterbusters.com)) and/or with John H. Halpern, M.D. of McLean Hospital and Harvard Medical School ([john\\_halpern@hms.harvard.edu](mailto:john_halpern@hms.harvard.edu)). Please try to enter your experiences as accurately and completely as possible. This diary is similar in design to one Dr. Halpern and Clusterbusters are intending to use in clinical research studies for developing new treatments for cluster headache. Your familiarity with this diary, then, may help us with evaluating you for possible participation in these future studies, but it is not required. In fact, you are free to take this diary and use it just for yourself. We hope your regular use of this diary will help you document and better inform your doctors and other healthcare providers about your cluster headaches. Consistent documentation with this diary can help confirm your diagnosis, if you have a new doctor or someone actually doubts you. This diary may also help you identify trends and changes in your symptoms and just how effective treatments are for your cluster headaches.

This diary has four different sections designed to record information regarding several different dimensions of cluster headache and its treatment.

**I.** Below, on this page, is the section to record preventive or long-term medications used for cluster headache. It also asks you if you've tried one of the treatments discussed at [www.clusterbusters.com](http://www.clusterbusters.com).

**II.** Pages 2 and 3 are for recording specific details of each cluster headache attack and the treatment for each attack. Please be sure to fill out both of these pages for each attack. You will need to print out Pages 2 and 3 a lot: they are only for describing what happens for one single headache attack. Details about your next headache attack are to be written on a new Page 2 and Page 3.

**III.** Page 4 is for recording the warning signs and symptoms that occur between cluster headache attacks. Please fill out one Page 4 sheet for each day the cluster cycle continues.

**IV.** Page 5 is for recording the total number of attacks, their intensity, and their duration over a month-long period; use a second sheet to record more days if needed.

Finally, Page 6 includes the International Headache Society's definition of Cluster Headache so that you can be aware of the criteria and symptoms used in medicine to diagnose you with this condition.

**I. Please list active medication(s) and/or other treatments for treating cluster headache here. Medications used to treat a single attack should NOT get listed here, but on a "Page 3" sheet that details treatments for a single attack.**

**CHECK IF NONE**

CLUSTER HEADACHE MEDICATIONS/TREATMENTS ONLY				START DATE (Mo-Day-Yr)	STOP DATE (Mo-Day-Yr)
Name of Medication or Other Treatment (such as dietary supplement, exercise, activity)	Oral/Inhaled/ Injected (if relevant)	Dosage (if relevant)	How often do you take this treatment? (dosage frequency)		

Have you had a "Clusterbusters discussed" treatment yet?      **YES**    **NO** (circle one). Today's Date: \_\_\_\_\_

If YES, does your experience of this reported cluster headache attack suggest to you that you are experiencing:

**IMPROVEMENT**      **WORSENING**      **NO CHANGE**      (circle one) in your cluster headache illness.

If you believe you are experiencing a change in your cluster headaches, what do you notice?:

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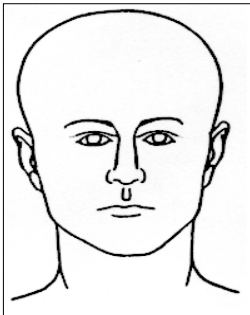
II. PLEASE FILL OUT A "PAGE 2" & "PAGE 3" SHEET FOR EACH ATTACK YOU HAD TODAY. USE NEW SHEETS FOR SEPERATELY DOCUMENTING EACH ATTACK.

THIS IS REPORTING ON HEADACHE ATTACK # \_\_\_\_\_ OF TODAY: DATE: \_\_\_\_\_  
 DID YOU DRINK ALCOHOL TODAY? Y/N: \_\_\_\_\_

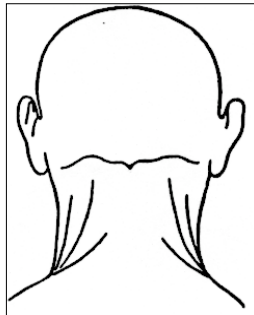
TOTAL # OF MINUTES FOR THIS ATTACK: \_\_\_\_\_

[Optional: TIME ATTACK STARTED: \_\_\_\_\_ TIME ATTACK ENDED: \_\_\_\_\_ ]

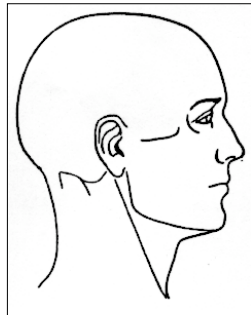
Please describe the location of your headaches. Use the head diagram, using the symbols on the chart below to show the headache location. \_\_\_\_\_



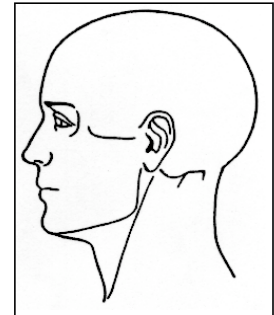
Front



Back



Right



Left

**Sensation Symbols**

Please mark on head diagrams the sensation and location that most accurately describes your headache.

**Throbbing = T**

**Dull Ache = A**

**Sharp/Stabbing = S**

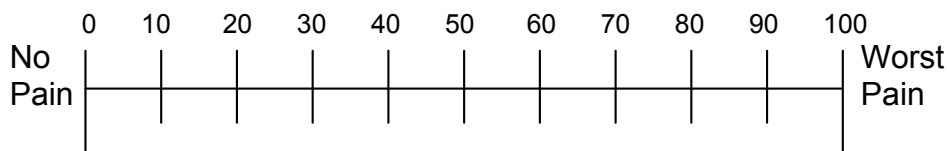
**Burning = B**

Which of the following symptoms did you experience during this headache attack):

Symptom	Check if YES	If YES, is symptom on same side as headache pain? YES/NO
My eye and/or the inside of my eyelid looked red and inflamed: "RED EYE"		
Tears were flowing from my eye		
My nose was congested/stuffy		
My nose was runny		
My forehead and/or face was sweating		
The pupil of my eye became smaller (like a "pinhole")		
My upper eyelid drooped down		
My eyelid swelled up/became puffy		
Other (what?: )		
Other (what?: )		
I felt restless or agitated during this attack		XXXXXXXXXXXXXXXXXXXX

**VISUAL ANALOG PAIN SCALE SCORE:** \_\_\_\_\_ (use metric ruler to accurately measure to the millimeter where your slash crosses through or approximate using the marker points provided at every centimeter)

Draw a single slash through the following to indicate the severity of pain of this headache (your answer MUST cross through the line from either end to somewhere in between!):



THIS PAGE IS A CONTINUATION OF REPORTING INFORMATION ON THE SAME HEADACHE ATTACK # \_\_\_\_\_ FOR TODAY FROM PAGE 2.

If you used a medication or other treatment because of this single headache attack, please fill out the following. Non-medication treatments can also be listed here.

CHECK IF NONE

TREATMENTS FOR ONLY THIS SPECIFIC CLUSTER HEADACHE ATTACK					Did you try this treatment again today for this specific attack? (Yes/No). If "Yes," please enter information about it on another separate line.	List reasons for use (for example, stop headache earlier; decrease pain; distraction)	Provide a number between 0 & 100 where 0 = not effective at all & 100 = 100% effective
NAME of MEDICATION (and dosage) or OTHER TREATMENT (such as herb, exercise, anything you do to try to treat this attack)	How many minutes into this attack did you start this treatment?	If relevant: Oral/Inhaled/ Injected	If you used Oxygen during this attack				How effective was this treatment in achieving stated reason for use
			Flow rate	Provide your best estimate of the number of minutes you used Oxygen			

Remember to fill out a "Page 2" and this page, "Page 3," for each headache attack!!

**TODAY'S DATE IS:** \_\_\_\_\_

**III. SYMPTOMS YOU ASSOCIATE WITH CLUSTER HEADACHE:**

Did you today experience any symptoms that you associate with soon having a cluster headache? If the answer is "YES" then you can document these symptoms below. Please remember that these are symptoms you experience outside the time of cluster headache attacks! These symptoms can occur on days that you do have attacks and also on days that you don't have attacks!

<b>SYMPTOM</b>	If you had this symptom today, write "YES" in the corresponding box below	<b>HOW INTENSE DID YOU EXPERIENCE THIS SYMPTOM TODAY?</b> (write a # 0 to 100 with 0 = weakest possible experience of symptom & 100 = most severe/intense/painful experience of this symptom)	<b>HOW ACCURATE IS THIS SYMPTOM STILL PREDICTING HAVING A CLUSTER HEADACHE SOON?</b> (write a # 0 to 100 with 0 = not accurate at all & 100 = 100% definite leading to a new attack)
<i>Brief period of extreme fatigue</i>			
<i>Neck pain or stiffness</i>			
<i>Pain in temple area</i>			
<i>Pain in jaw area</i>			
<i>Pain in other specific area (where? _____)</i>			
<i>Tears flowed from my eye</i>			
<i>My eye and/or the inside of my eyelid looked red and inflamed: "RED EYE"</i>			
<i>My eyelid swelled up/became puffy</i>			
<i>The pupil of my eye became smaller (like a "pinhole")</i>			
<i>My nose was congested/stuffy</i>			
<i>My nose was runny</i>			
<i>Mental cloudiness/confusion</i>			
<i>Change in sleep pattern</i>			
<i>Alcohol triggers headache attack</i>			
<i>Other (what? _____)</i>			
<i>Other (what? _____)</i>			
<i>Other (what? _____)</i>			
<i>Other (what? _____)</i>			



**International Headache Society Description of Cluster Headache:**

Attacks of severe, strictly unilateral (one-sided) pain which is orbital (the area of your eye socket “behind your eye”), supraorbital (the area around your eye socket), temporal (area of your temple to the side of your eye) or in any combination of these sites, lasting **15-180** minutes and occurring from once every other day to 8 times a day. Pain is maximal orbitally, supraorbitally, temporally or in any combination of these sites, but may spread to other regions of the head. Pain almost invariably recurs on the same side during an individual cluster period. During the worst attacks, the intensity of pain is excruciating. Patients are usually unable to lie down and characteristically pace the floor. The attacks are associated with one or more of the following, all of which are ipsilateral (on the same side of the head as the headache pain): conjunctival injection (the mucous membrane that covers the front of the eye and lines the inside of the eyelids looks red/inflamed: “red eye”), lacrimation (the flow of tears), nasal congestion, rhinorrhea (nasal discharge/“runny nose”), forehead and facial sweating, miosis (excessive constriction/tightening of the eye’s pupil), ptosis (drooping of the upper eyelid), eyelid edema (swelling/“puffiness” of the eyelid from excessive watery fluid collection). Most patients are restless or agitated during an attack.

**Diagnostic criteria:**

- A. At least 5 attacks fulfilling criteria B-D.
- B. Severe or very severe unilateral orbital, supraorbital and/or temporal pain lasting 15-180 minutes if untreated.<sup>1</sup>
- C. Headache is accompanied by at least one of the following (all medical terms defined above):
  - 1. ipsilateral conjunctival injection and/or lacrimation
  - 2. ipsilateral nasal congestion and/or rhinorrhoea
  - 3. ipsilateral eyelid edema
  - 4. ipsilateral forehead and facial sweating
  - 5. ipsilateral miosis and/or ptosis
  - 6. a sense of restlessness or agitation
- D. Attacks have a frequency from one every other day to 8 per day.<sup>2</sup>
- E. Not attributed to another disorder.

**Note:**

<sup>1</sup> During part (but less than half) of the time-course of cluster headache, attacks may be less severe and/or of shorter or longer duration.

<sup>2</sup> During part (but less than half) of the time-course of cluster headache, attacks may be less frequent.

**For Episodic Cluster Headache:****Description:**

Cluster headache attacks occurring in cycles lasting 7 days to 1 year separated by pain-free periods lasting 1 month or longer.

**Diagnostic criteria:**

- F. Attacks fulfilling criteria A-E above
- G. At least two cluster cycles lasting 7-365 days<sup>3</sup> and separated by pain-free remission periods of  $\geq 1$  month.

**Note:** <sup>3</sup> Cluster cycles usually last between 2 weeks and 3 months.

**Comment:** The duration of the remission period has been increased in the most recent edition of HIS diagnostic criteria to a minimum of 1 month.

**For Chronic Cluster Headache:****Description:**

Cluster headache attacks occurring for more than 1 year without remission or with remissions lasting less than 1 month.

**Diagnostic criteria:**

- H. Attacks fulfilling criteria A-E for 3.1 **Cluster headache**
- I. Attacks recur over  $>1$  year without remission periods or with remission periods lasting  $<1$  month

**Comment:**

Chronic cluster headache may arise **de novo** (previously referred to as **primary chronic cluster headache**) or evolve from the episodic subtype (previously referred to as **secondary chronic cluster headache**). Some patients may switch from chronic to episodic cluster headache.