Cluster Headache Questionnaire Survey - Official

SV Welcome to the Cluster Headache Questionnaire (CHQ) survey. This study is being conducted by Dr. Larry Schor (Principle Investigator) and Stuart Pearson (Graduate Research Assistant) with the approval of the Institutional Review Board (IRB) at the University of West Georgia. The purpose of this survey is to better understand and expand the current body of research on Cluster Headaches. As you'll see, we intend to focus primarily on five areas: 1. Demographics, which means we we will ask some questions about your age, employment, where you live, etc. 2. Treatments you have used for your attacks. 3. Experience of pain. 4. Emotional burden and suicidality. 5. How this condition impacts work, relationships, and quality of life. Your participation will substantially help contribute to the body of research. Click next to continue...

IC All information on this survey will be held confidential by the principle investigator, project coordinator, and research assistants. At no time will your personally identifiable information (PII) be shared with anyone outside the research team. At the end of the survey, we will ask if you would like to share your contact information so we might follow up with you about your responses. You may decline to share. Information we collect will be specific to Cluster Headache attacks and treatment as specified on the previous screen. **Additionally, you must be 18 years of age or older to take this survey.** Based on the above, click "agree" or "disagree" below to provide your consent to participate in this survey:

Agree

Disagree

HELP Because Cluster Headache is associated with increased risk of suicide, we'd like to share some resources with you. If you are currently struggling with thoughts or feelings of suicide, please click on the below resources to find help and support in your area.

International Lines
Inside the US by State
For facts, information, support and resources about cluster headache and suicide, click to download these attachments:

Cluster Headache and Suicide

Pacts About Cluster Headache Brochure Click next to continue...

SCR1 In this section, we'd like to ask you some specific questions about your condition. Click next to continue:

Diagnosis I have been diagnosed with Cluster Headache by a medical professional. Indicate yes or no:

Yes

No

G44.0 Do you have any of the following symptoms at any time in any attack? Please read each carefully.

YES NO Is your pain extremely severe and only on one side, above the eye, or around the temple? Swelling and redness of the eye lining and flow of tears on the same side as the pain Swelling, redness, and congestion of the nose on the same side as the pain Puffiness and swelling of the eyelid on the same side as the pain Sweating on the forehead and face on the same side as the pain Very small pupil and/or drooping eye lid on the same side as the pain A sense of fullness in the ear on the same side as the pain. A sense of restlessness or agitation Severe or very severe pain occurring on both sides of the head during a single Cluster attack Nausea and Vomiting Over sensitivity to light or sound Does physical activity like walking and climbing stairs aggravate or worsen the pain? No other condition can explain these attacks

P1A How many total Cluster Headache attacks do you estimate you've endured in your entire life? This can be a rough number, but get as close as you can.



FREQ Have you been diagnosed as Chronic or Episodic?

Episodic

Chronic

Both

Display This Question:

If Have you been diagnosed as Chronic or Episodic? = Both

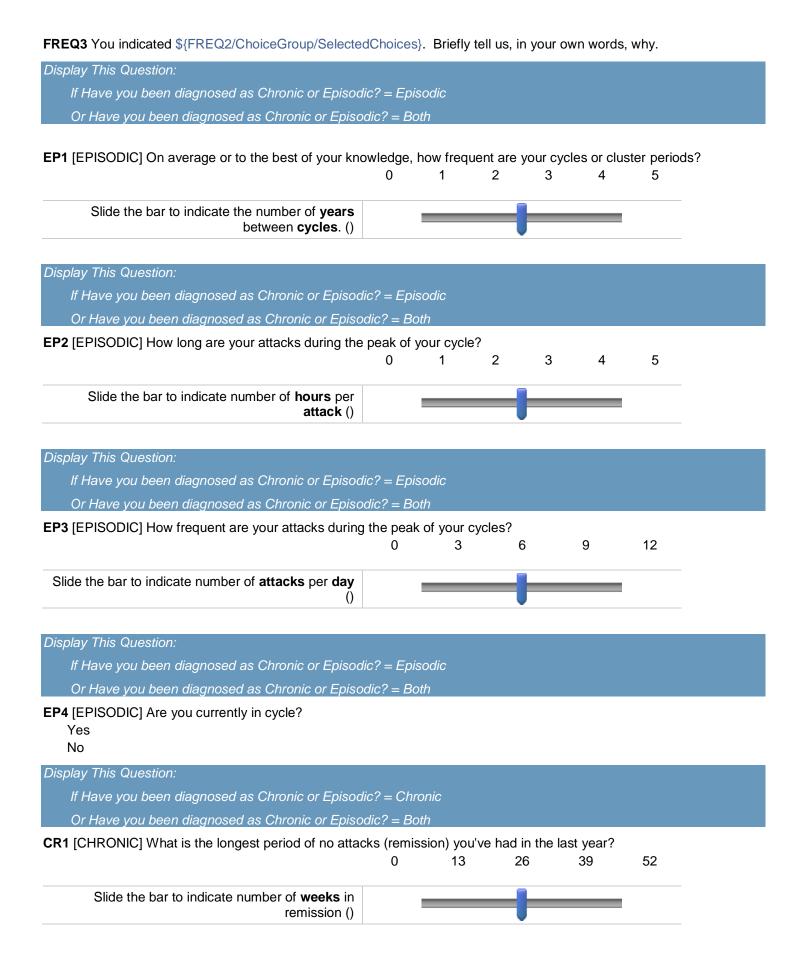
FREQ2 You've indicated that you have been diagnosed as "Both." You will be asked questions about your experience under both circumstances. If you have been diagnosed as both chronic and episodic, or if you have been episodic and become chronic or been chronic and become episodic, which condition was more burdensome?

Episodic

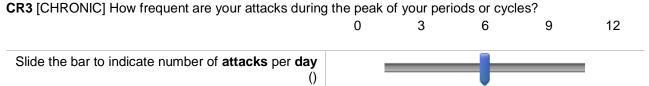
Chronic

Display This Question:

If Have you been diagnosed as Chronic or Episodic? = Both



Display This Question: If Have you been diagnosed as Chronic or Episodic? = Chronic Or Have you been diagnosed as Chronic or Episodic? = Both CR2 [CHRONIC] How long are your attacks? 0 1 2 3 4 5 Slide the bar to indicate number of hours per attack () Display This Question: If Have you been diagnosed as Chronic or Episodic? = Chronic Or Have you been diagnosed as Chronic or Episodic? = Both



Dem Demographics: This section will ask some basic demographic questions that will help us understand a little more about you, your history with Cluster Headache attacks, and your experience with Cluster Headache attacks. Please answer to the best of your knowledge. Click next to continue...

D1 Tell us your gender:

Male

Female

Other

Decline to say

D1A What is your country of residence? Please select your country of residence

▼ United States ... Zimbabwe ~ ~ ~ ~ ~ ~ ~ ~ ~ ~ (2497)

D1B What type of currency do you use?

Dollars

Pound

Franc

Peso

Euro

Ruble

Yuan

Yen

Won (9)

Other: (10)

D2 We'd like to know what age you were when you experienced your first Cluster Headache attack, how old you were when you were first diagnosed, and how old you are now. Drag the slider to the right to indicate the age appropriate to each category.

	0	25	50	75	100
Age of Onset			-		
Age at 1st Diagnosis					
Current Age					

D3 Do you know of anyone else in your family who has also suffered from Cluster Headaches attacks?

Yes

No

Maybe (please select if you suspect a family member went undiagnosed)

Skip To: D5 If Do you know of anyone else in your family who has also suffered from Cluster Headaches attacks? = No

D4 Please indicate if any of your biological relatives have ever struggled with Cluster Headache attacks. Check all that apply:

Parent

Sibling

Child

Other: (type additional below)
Other: (type additional below)

D5 Are you currently employed?

Full time (Salaried)

Full time (Hourly)

Part time (Hourly)

Independent Contractor

Self Employed / Freelance

Unemployed

Other:

D6 Tell us about your career field.

▼ ------Select Answer from list----- (30) ... Other (59)

D7 Have you ever applied for disability compensation due to Cluster Headache attacks?

Yes

No

Display This Question:

If Have you ever applied for disability compensation due to Cluster Headache attacks? = Yes

D7A What is the current disposition of your disability request?

Currently on Full Disability

Currently on Partial Disability

Request currently pending approval

Denied once

Denied multiple times

Other, please specify:

Display This Question:

If Have you ever applied for disability compensation due to Cluster Headache attacks? = No

D7B What has prevented you from applying for disability compensations? Check all that apply:

I think I can manage the pain and don't need disability.

I did not think Cluster Headache was covered.

I've heard horror stories about doing the paper work required.

I don't want to take support away from someone else who needs it more.

I just don't want to bother.

Other, please specify:

EXP In this section, we'd like to know more about the pain you've experienced associated with Cluster Headache attacks. Click next to continue...

P1 Have you ever experienced anything more painful than Cluster Headaches?

Yes

No

P2 The following is a partial list of other very painful conditions. If you've ever experienced any of the following, please indicate below. If you've experienced any other painful condition that is not listed below, please write it in the boxes marked "other" so that we may compare. Check all that apply:

Child birth

Migraine

Shingles

Broken Bones

Heart Attack

Herniated Disk (i.e. slipped disk)

Arthritis

Sciatica

Kidney Stones

Gall Stones

Pancreatitis

Fibromyalgia

Spinal Tap

Gunshot wound

Stab wound (15)

Biopsy (Kidney, Spleen, Liver, Bone Marrow or other major organ)

Other

Other

Other

Skip To: PSY If Selected Choices < 1

Carry Forward Selected Choices - Entered Text from "The following is a partial list of other very painful conditions. If you've ever experienced any of the following, please indicate below. If you've experienced any other painful condition that is not listed below, please write it in the boxes marked "other" so that we may compare. Check all that apply:

P3 Comparing each experience with Cluster Headache attacks, how painful would you rate each on a scale of 1 (least painful) to 10 (most painful)?

Indicate how painful each is by sliding the bar to the right.

	0	2	4	6	8	10
Child birth ()						_
Migraine ()				Ť		_
Shingles ()				Ì		_
Broken Bones ()						_
Heart Attack ()						_
Herniated Disk (i.e. slipped disk) ()						_
Arthritis ()						_
Sciatica ()						_
Kidney Stones ()						_
Gall Stones ()						_
Pancreatitis ()						
Fibromyalgia ()						
Spinal Tap ()						
Gunshot wound ()						_
Stab wound ()						
Biopsy (Kidney, Spleen, Liver, Bone Marrow or other major	organ) ()					
Other ()						_
Other ()						_
Other ()						_

HT Did you ever experience a significant head trauma(s) prior to the development of your Cluster Headache attacks?

No

Display This Question:

If Did you ever experience a significant head trauma(s) prior to the development of your Cluster Hea... = Yes

HT2 Please explain the circumstances of your head trauma below:

PLoc In the next few questions, you will be given an opportunity to view four pictures of a human head. Click on the regions of the face and head that correspond to the locations where you experience pain during Cluster Headache attacks. You have 10 available "clicks" per picture to identify where pain is located on your head. Placing each click at the same area will reflect intensity. Place clicks farther apart will reflect less intensity. If there is no pain that typically corresponds to the picture shown then click next. To begin, please specify which side of your head you experience pain from attacks.

Left Side Right Side Both

PLoc1 Anterior (FRONT) View: Click on the regions where your pain is present during an attack for this view. (IMAGE IS RIGHT / LEFT REVERSED)



PLoc2 Posterior View: Click on the regions where your pain is present during an attack for this view.



Display This Question:

If In the next few questions, you will be given an opportunity to view four pictures of a human head... = Right Side

Or In the next few questions, you will be given an opportunity to view four pictures of a human head... = Both

PLoc3 Right Sagittal View: Click on the regions where your pain is present during an attack for this view.



Display This Question:

If In the next few questions, you will be given an opportunity to view four pictures of a human head... = Left Side

Or In the next few questions, you will be given an opportunity to view four pictures of a human head... = Both

PLoc4 Left Sagittal View: Click on the regions where your pain is present during an attack for this view.



PSY We'd like you to share some about the psychological suffering and impact of Cluster Headache attacks. Click next to continue...

PSY1 The following is a list of questions related to the **psychological**, **social**, **and vocational** impact of your experience with Cluster Headache attacks. Answer each question within the context of your struggle with Cluster Headache diagnosis: **i.e.** "As a result of your experience with Cluster Headaches."

	Never	Once
Have you felt sad or hopeless about your future due to your condition?		
Do you often believe you are a burden to loved ones?		
Do you often feel disconnected from the world? As though you don't belong?		
Have you ever felt isolated?		
Are you unable to engage in social or leisure activities?		
Do you often avoid contact with friends and family?		
Do you ever fear that people won't understand you or your struggle with Cluster headache?		
Have you ever been unable to perform duties at work?		
Have you had trouble focusing on important tasks?		
How often do you fear losing your job?		
Have you considered early retirement?		
Have you lost jobs?		
Has your condition interfered with romantic relationships?		
Has your condition led to a break up?		
Are you unable to complete household chores?		
Are you unable to leave the house?		
Do you often feel like lying down in a quiet and secluded place during your attacks?		
Do you often feel like pacing, rocking, or other movement to distract yourself or cope with the pain?		
Do you experience difficulties getting to sleep or staying asleep?		
Do you have trouble maintaining a healthy diet and appetite?		
Have you been unable to maintain fitness and exercise?		
Do you struggle to maintain a consistent body weight (either too high or too low)?		
When out of cycle or in remission, do you often struggle with fear, anxiety, and/or dread of your next attack?		
When you are in cycle but not having an attack, do you struggle with fear, anxiety, and/or dread of your next attack?		
When out of cycle or in remission, do you find yourself obsessing over the next attack? (29)		
During an attack , do you engage in self injurious behavior? (head banging, hitting, biting etc)		
During an attack , have you ever considered or contemplated suicide?		
	i e	

Most of the time

Rarely Sometimes

All the time

When out of cycle or in remission, have you ever contemplated or considered suicide?

Have you ever attempted suicide?

Anything else you want us to know about? Other impact?

FINa Overall, how would you rate the financial burden placed on you due to Cluster Headaches?

Minimal

Somewhat Burdensome

Very Burdensome

Severe

Completely Unmanageable

FIN Have your Cluster Headaches caused you to go to the hospital or the emergency room?

Yes

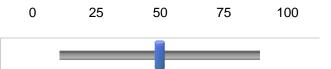
No

Display This Question:

If Have your Cluster Headaches caused you to go to the hospital or the emergency room? = Yes

Visits ()

FIN1 How many times have you been to the hospital?



Display This Question:

If Have your Cluster Headaches caused you to go to the hospital or the emergency room? = Yes

FIN2 How would you rate your financial burden due to hospital visits?

Minimal

Somewhat Burdensome

Very Burdensome

Severe

Completely Unmanageable

Display This Question:

If Have your Cluster Headaches caused you to go to the hospital or the emergency room? = Yes

FIN2A What sort of financial burden have arisen due to hospital visits? Estimate to the best of your knowledge:



PSY2 How have Cluster Headache attacks negatively affected your mental health or emotional well being?

None (0)

Minimally

Moderately

Severely

PSY3 Have you sought mental health counseling or other professional support related to Cluster Headache?

Yes

No

Decline to Answer

Display This Question:

If Have you sought mental health counseling or other professional support related to Cluster Headache? = Yes

PSY4 Was your mental health counseling helpful?

Not at all (0)

A little

Somewhat

Very

Display This Question:

If Have you sought mental health counseling or other professional support related to Cluster Headache? = No

PSY5 What has prevented you from seeking mental health support?

Not sure its helpful

Couldn't afford

Not covered by health plan

Other, please explain:

MED In this section, we'd like to know about the types of medications, treatments, and operations you've tried or are currently using in order to prevent Cluster Headache cycles or abort an attack, how effective they were, and how difficult they were to obtain. Click next to continue...

MP Preventive Medication refers to any medication that you have taken or currently take on a daily or recurring basis to prevent future Cluster Headache attacks. Have you ever tried preventive medications?

Yes

No

Decline to Answer

Skip To: MA If Preventive Medication refers to any medication that you have taken or currently take on a daily o... != Yes

MP1 Please indicate which preventive medications you've been prescribed. For this section, please only consider medication **legally available by prescription** from a qualified physician. Check all that apply:

Calcium Channel Blockers (Verapamil, Flunarizine, Amlodipine, Diltiazem)

Corticosteroids (Flumedroxone, Prednisone, Cortisone)

Beta-Blockers (Propranolol, Timolol, Metoprolol, Nadolol, Atenolol)

Lithium (Lithobid)

Methysergide (Sansert) or methylergonovine (Methergine)

Anticonvulsants (Topiramate, Valproate, Carbamazapine, Oxcarbazepine, Gabapenin, Pregabalin)

Testosterone

Other

Other (9)

Carry Forward Selected Choices - Entered Text from "Please indicate which preventive medications you've been prescribed. For this section, please only consider medication legally available by prescription from a qualified physician. Check all that apply:"

MP2 How effective is each medication in preventing CH?

Unsure	Completely Ineffective	Minimally effective	Somewhat effective	Very effective	Completely Effective
	Unsure	I IIngiira · · ·	I Inghra	Inghr	Inghia

Carry Forward Selected Choices - Entered Text from "Please indicate which preventive medications you've been prescribed. For this section, please only consider medication legally available by prescription from a qualified physician. Check all that apply:"

MP3 We'd like to know how difficult it was to obtain each of these medications:

No Difficulty	Slight Difficulty	Some Difficulty	Extreme Difficulty	Unable to Get
		•	<u> </u>	•

Carry Forward Selected Choices - Entered Text from "Please indicate which preventive medications you've been prescribed. For this section, please only consider medication legally available by prescription from a qualified physician. Check all that apply:"

MP4 Did you experience any psychological or emotional complications from the use of these medications?

	None	Minimal Complications	Some complications	Severe Complications
Calcium Channel Blockers (Verapamil, Flunarizine, Amlodipine, Diltiazem)				
Corticosteroids (Flumedroxone, Prednisone, Cortisone)				
Beta-Blockers (Propranolol, Timolol, Metoprolol, Nadolol, Atenolol)				
Lithium (Lithobid)				
Methysergide (Sansert) or methylergonovine (Methergine)				
Anticonvulsants (Topiramate, Valproate, Carbamazapine, Oxcarbazepine, Gabapenin, Pregabalin)				
Testosterone				
Other				
Other				

Display This Question:

If Did you experience any psychological or emotional complications from the use of these medications? [Severe Complications] (Count) >= 1

Carry Forward Selected Choices from "Did you experience any psychological or emotional complications from the use of these medications?"

MP4A You indicated that you had severe complications with: \${MP4/ChoiceGroup/SelectedChoicesForAnswer/3}. What kind of complications did you experience? Please include as much detail as possible. (For example, the medication worked well but made me feel awful...)

Carry Forward Selected Choices - Entered Text from "Please indicate which preventive medications you've been prescribed. For this section, please only consider medication legally available by prescription from a qualified physician. Check all that apply:"

MP5 Did you experience any **physical** or **medical** complications from the use of these medications?

	None	Minimal Complications	Some complications	Severe Complications
Calcium Channel Blockers (Verapamil, Flunarizine, Amlodipine, Diltiazem)				
Corticosteroids (Flumedroxone, Prednisone, Cortisone)				
Beta-Blockers (Propranolol, Timolol, Metoprolol, Nadolol, Atenolol)				
Lithium (Lithobid)				
Methysergide (Sansert) or methylergonovine (Methergine)				
Anticonvulsants (Topiramate, Valproate, Carbamazapine, Oxcarbazepine, Gabapenin, Pregabalin)				
Testosterone				
Other				
Other				

Display This Question:

If Did you experience any physical or medical complications from the use of these medications? [Severe Complications] (Count) >= 1

Carry Forward Selected Choices from "Did you experience any physical or medical complications from the use of these medications?"

MP5A You indicated that you had severe complications

with: \${MP5/ChoiceGroup/SelectedChoicesForAnswer/3}. What kind of complications did you experience? Please include as much detail as possible. (For example, the medication worked well but made me feel awful...)

MA **Abortive (Acute) Medication** refers to any medication that you have taken or currently take when you feel a Cluster Headache attack developing with the hope of aborting or ending the particular attack. Have you ever tried abortive medications?

Yes

No

Decline to Answer

Skip To: MS If Abortive (Acute) Medication refers to any medication that you have taken or currently take when y... != Yes

MA1 Please indicate which **abortive medications** you've been prescribed. For this section, please only consider medication <u>legally available</u> by prescription from a qualified physician. Check all that apply:

Triptans (Almotriptan, Avitriptan, Eletriptan, Frovatriptan, Naratriptan, Rizatriptan, Sumatriptan, Zolmitriptan, Treximet) 100% Oxygen

Cafergot / ergotomine

Intranasal Ketamine

Lidocaine Nasal Drops

DHE - IV, Nasal (Migranal)

Intranasal Capsaicin

Opiates (Morphine, Oxycodone, Hydrocodone)

Other: Other:

Carry Forward Selected Choices - Entered Text from "Please indicate which abortive medications you've been prescribed. For this section, please only consider medication legally available by prescription from a qualified physician. Check all that apply:"

MA2 How effective is each medication in aborting Cluster Headache attacks?

	Unsure	Completely Ineffective	Minimally effective	Somewhat effective	Very effective	Completely Effective
Triptans (Almotriptan, Avitriptan, Eletriptan, Frovatriptan, Naratriptan, Rizatriptan, Sumatriptan, Zolmitriptan, Treximet)						
100% Oxygen						
Cafergot / ergotomine						
Intranasal Ketamine						
Lidocaine Nasal Drops						
DHE - IV, Nasal (Migranal)						
Intranasal Capsaicin						
Opiates (Morphine, Oxycodone, Hydrocodone)						
Other:						
Other:						
Other:						

Camaaydaat

1/000

Camanlatali

Carry Forward Selected Choices - Entered Text from "Please indicate which abortive medications you've been prescribed. For this section, please only consider medication legally available by prescription from a qualified physician. Check all that apply:"

MA3 We'd like to know how difficult it was to obtain each of these medications:

Triptans (Almotriptan, Avitriptan, Eletriptan, Frovatriptan, Naratriptan, Rizatriptan, Sumatriptan, Zolmitriptan, Treximet) 100% Oxygen Cafergot / ergotomine Intranasal Ketamine Lidocaine Nasal Drops		No Difficulty	Slight Difficulty	Some Difficulty	Extreme Difficulty	Unable to Get
Cafergot / ergotomine Intranasal Ketamine						
Intranasal Ketamine	100% Oxygen					
	Cafergot / ergotomine					
Lidocaine Nasal Drops	Intranasal Ketamine					
	Lidocaine Nasal Drops					
DHE - IV, Nasal (Migranal)	DHE - IV, Nasal (Migranal)					
Intranasal Capsaicin	Intranasal Capsaicin					
Opiates (Morphine, Oxycodone, Hydrocodone)	Opiates (Morphine, Oxycodone, Hydrocodone)					
Other:	Other:					
Other:	Other:					
Other:	Other:					

Carry Forward Selected Choices - Entered Text from "Please indicate which abortive medications you've been prescribed. For this section, please only consider medication legally available by prescription from a qualified physician. Check all that apply:"

MA4 Did you experience any psychological or emotional complications from the use of these medications?

	None	Minimal Complications	Some complications	Severe Complicati ons
Triptans (Almotriptan, Avitriptan, Eletriptan, Frovatriptan, Naratriptan, Rizatriptan, Sumatriptan, Zolmitriptan, Treximet)				
100% Oxygen				
Cafergot / ergotomine				
Intranasal Ketamine				
Lidocaine Nasal Drops				
DHE - IV, Nasal (Migranal)				
Intranasal Capsaicin				
Opiates (Morphine, Oxycodone, Hydrocodone)				
Other:				
Other:				

Display This Question:

If Did you experience any psychological or emotional complications from the use of these medications? [Severe Complications] (Count) >= 1

Carry Forward Selected Choices from "Did you experience any psychological or emotional complications from the use of these medications?"

MA4A You indicated that you had severe complications

with: \${MA4/ChoiceGroup/SelectedChoicesForAnswer/3}. What kind of complications did you experience? Please include as much detail as possible. (For example, the medication worked well but made me feel awful...)

Carry Forward Selected Choices - Entered Text from "Please indicate which abortive medications you've been prescribed. For this section, please only consider medication legally available by prescription from a qualified physician. Check all that apply:"

MA5 Did you experience any physical or medical complications from the use of these medications?

None	Minimal Complications	Some complications	Severe Complications
	None	None	None

Display This Question:

If Did you experience any physical or medical complications from the use of these medications? [Severe Complications] (Count) >= 1

Carry Forward Selected Choices from "Did you experience any physical or medical complications from the use of these medications?"

MA5A You indicated that you had severe complications

with: \$\{\text{MA5/ChoiceGroup/SelectedChoicesForAnswer/3}\}. What kind of complications did you experience? Please include as much detail as possible. (For example, the medication worked well but made me feel awful...)

Display This Question:

If Please indicate which abortive medications you've been prescribed. For this section, please only... = 100% Oxygen

OXY You indicated that you have been prescribed or used 100% Oxygen. How long did it take you get a prescription for 100% Oxygen after you received your Cluster Headache diagnosis?

Greater than 4 Years

0 12 24 36 48



Display This Question:

If Please indicate which abortive medications you've been prescribed. For this section, please only... = 100% Oxygen

And Did you experience any psychological or emotional complications from the use of these medications? 100%

Oxygen - None Is Selected

And Did you experience any physical or medical complications from the use of these medications? 100% Oxygen - None Is Selected

OXY2 You've indicated that a) you have used 100% Oxygen to treat your Cluster Headaches and b) that you experienced no side effects, adverse effects, or complications. How many total cluster attacks would you estimate you have successfully treated in your lifetime?



Display This Question:

If Please indicate which abortive medications you've been prescribed. For this section, please only... != 100% Oxygen

OXY3 You indicated that you have not tried 100% Oxygen. Did you ask your doctor for a prescription?

Yes

No

Display This Question:

If You indicated that you have not tried 100% Oxygen. Did you ask your doctor for a prescription? = Yes

OXY4 What prevented you obtaining 100% Oxygen for your Cluster Headache attacks?

I was given a prescription but my insurance would not cover it.

I was given a prescription but Medicare would not cover it.

I was denied a prescription because my doctor did not believe it to be effective.

I was denied a prescription because my doctor felt it was unsafe for me due to a comorbid condition (ex. COPD). Other:

MS Out of desperation or a lack of effective treatment options available, have you ever resorted to using any **legally prohibited or unregulated substances** as either **preventive** or **abortive** in managing your Cluster Headache attacks? Reminder: Your answers will remain confidential. Please answer to the best of your ability.

Yes

No

Decline to answer

Skip To: OP If Out of desperation or a lack of effective treatment options available, have you ever resorted to... != Yes

MS1 What substances have you tried? Check all that apply:

Psilocybin (mushrooms)

LSD

Bromo-LSD (BOL)

LSA (seeds, MG, HBW, RC)

Dimethyltryptamine (DMT, Ayahausca)

Marijuana

Kudzu

Melatonin

Energy Drinks (Monster, Red Bull, Rockstar,) (9)

Licorice Roots (10)

Other: (11) Other: (12) Other: (13)

Carry Forward Selected Choices - Entered Text from "What substances have you tried? Check all that apply:"

MS2 How effective is each substance in aborting cluster attacks?

	Unsure	Completely Ineffective	Minimally effective	Somewhat effective	Very effective	Completely Effective
Psilocybin (mushrooms)	0	\circ	\circ	\circ	\circ	\circ
LSD	0	\circ	\circ	\circ	\circ	\circ
Bromo-LSD (BOL)	0	\circ	\circ	\circ	\circ	\circ
LSA (seeds, MG, HBW, RC)	0	\circ	\circ	\circ	\circ	\circ
Dimethyltryptamine (DMT, Ayahausca)	0	\circ	\circ	\circ	\circ	\circ
Marijuana	0	\circ	\circ	\circ	\circ	\circ
Kudzu	0	\circ	\circ	\circ	\circ	\circ
Melatonin	0	\circ	\circ	\circ	\circ	\circ
Energy Drinks (Monster, Red Bull, Rockstar,)	0	\circ	0	0	\circ	\circ
Licorice Roots	0	\circ	\circ	\circ	\circ	\circ
Other: (x11)	0	\circ	\circ	\circ	\circ	\circ
Other: (x12)	0	\circ	\circ	\circ	\circ	\circ
Other: (x13)	0	\circ	0	\circ	\circ	\circ

Carry Forward Selected Choices - Entered Text from "What substances have you tried? Check all that apply:"

MS3 Did you experience any psychological or emotional complications from the use of these substances?

	None	Minimal Complications	Some Complications	Severe Complications
Psilocybin (mushrooms)	С	\circ	\circ	\circ
LSD	С	\circ	\circ	\circ
Bromo-LSD (BOL)	С	0	\circ	0
LSA (seeds, MG, HBW, RC)	С	\circ	0	0
Dimethyltryptamine (DMT, Ayahausca)	С	\circ	\circ	\circ
Marijuana	С	\circ	\circ	\circ
Kudzu	С	\circ	0	\circ
Melatonin	С	\circ	\circ	\circ
Energy Drinks (Monster, Red Bull, Rockstar,)	С	\circ	\circ	\circ
Licorice Roots	С	\circ	\circ	\circ
Other: (x11)	С	\circ	\circ	\circ
Other: (x12)	С	\circ	\circ	\circ
Other: (x13)	С	\circ	\circ	\circ

Display This Question:

If Did you experience any psychological or emotional complications from the use of these substances? [Severe Complications] (Count) >= 1

Carry Forward Selected Choices from "Did you experience any psychological or emotional complications from the use of these substances?"

MS3A You indicated that you had severe complications

with: \${MS3/ChoiceGroup/SelectedChoicesForAnswer/3}. What kind of complications did you experience? Please include as much detail as possible. (For example, the substance worked well but made me feel awful...)

Carry Forward Selected Choices - Entered Text from "What substances have you tried? Check all that apply:"

MS4 Did you experience any physical or medical complications from this medication?

	None	Minimal Complications	Some Complications	Severe Complications
Psilocybin (mushrooms)				
LSD				
Bromo-LSD (BOL)				
LSA (seeds, MG, HBW, RC)				
Dimethyltryptamine (DMT, Ayahausca)				
Marijuana				
Kudzu				
Melatonin				
Energy Drinks (Monster, Red Bull, Rockstar,)				
Licorice Roots				
Other: (x11)				
Other: (x12)				
Other: (x13)				

Display This Question:

If Did you experience any physical or medical complications from this medication? [Severe Complications] (Count)

Carry Forward Selected Choices from "Did you experience any physical or medical complications from this medication?"

MS4A You indicated that you had severe complications

with: \$\{\text{MS4/ChoiceGroup/SelectedChoicesForAnswer/4}\}. What kind of complications did you experience? Please include as much detail as possible. (For example, the substance worked well but made me feel awful...)

OP In this section, we'd like to know about surgical or invasive procedures you've tried to reduce or eliminate your Cluster Headache attacks. Have you ever tried any surgical operations or invasive procedures?

Yes

No

Decline to Answer

Skip To: IMPL If In this section, we'd like to know about surgical or invasive procedures you've tried to reduce o... != Yes

OP1 Please indicate which **surgical procedures** you've tried. Check all that apply:

Tooth Extraction

Botulin Toxin Injection (Botox)

Micro-vascular Decompression

Radio Frequency Ablation

Nerve Block

Deep Brain Stimulation (DBS)

Transcranial Magnetic Stimulation (TMS)

Sphenopalatine Ganglion Block or Ablation

Sphenopalatine Ganglion Stimulation (9)

Vagus Nerve Stimulation (10)

Radio Frequency Modification (11)

Supraorbital Nerve Stimulation (12)

Occipital Nerve Stimulation (13)

Supraorbital Nerve and Occipital Nerve Combined Stimulation (14)

Auricular Nerve Stimulation (15)

Other: (16) Other: (17) Other: (18)

Carry Forward Selected Choices - Entered Text from "Please indicate which surgical procedures you've tried. Check all that apply:"

OP2 How effective was each surgical procedure in treating Cluster Headache	attacks?
---	----------

	Unsure	Completely Ineffective	Minimally effective	Somewhat effective	Very effective	Completely Effective
Tooth Extraction						
Botulin Toxin Injection (Botox)						
Micro-vascular Decompression						
Radio Frequency Ablation						
Nerve Block						
Deep Brain Stimulation (DBS)						
Transcranial Magnetic Stimulation (TMS)						
Sphenopalatine Ganglion Block or Ablation						
Sphenopalatine Ganglion Stimulation						
Vagus Nerve Stimulation						
Radio Frequency Modification						
Supraorbital Nerve Stimulation						
Occipital Nerve Stimulation						
Supraorbital Nerve and Occipital Nerve Combined Stimulation						
Auricular Nerve Stimulation						

Carry Forward Selected Choices - Entered Text from "Please indicate which surgical procedures you've tried. Cl all that apply:"

Check

OP3 Did you experience any **psychological** or **emotional** complications from these procedures?

	None	Minimal Complications	Some complications	Severe Complications
Tooth Extraction				
Botulin Toxin Injection (Botox)				
Micro-vascular Decompression				
Radio Frequency Ablation				
Nerve Block				
Deep Brain Stimulation (DBS)				
Transcranial Magnetic Stimulation (TMS)				
Sphenopalatine Ganglion Block or Ablation				
Sphenopalatine Ganglion Stimulation				
Vagus Nerve Stimulation				
Radio Frequency Modification				
Supraorbital Nerve Stimulation				
Occipital Nerve Stimulation				
Supraorbital Nerve and Occipital Nerve Combined Stimulation				
Auricular Nerve Stimulation				

Display This Question:

If Did you experience any psychological or emotional complications from these procedures? [Severe Complications] (Count) >= 1

Carry Forward Selected Choices from "Did you experience any psychological or emotional complications from these procedures?"

OP3A You indicated that you had severe complications with: \${OP3/ChoiceGroup/SelectedChoicesForAnswer/3}. What kind of complications did you experience? Please include as much detail as possible. (For example, the procedure worked well but made me feel awful...)

Carry Forward Selected Choices - Entered Text from "Please indicate which surgical procedures you've tried. Check all that apply:"

OP4 Did you experience any **physical** or **medical** complications from the use of these procedures?

	None	Minimal Complications	Some complications	Severe Complications
Tooth Extraction				
Botulin Toxin Injection (Botox)				
Micro-vascular Decompression				
Radio Frequency Ablation				
Nerve Block				
Deep Brain Stimulation (DBS)				
Transcranial Magnetic Stimulation (TMS)				
Sphenopalatine Ganglion Block or Ablation				
Sphenopalatine Ganglion Stimulation				
Vagus Nerve Stimulation				
Radio Frequency Modification				
Supraorbital Nerve Stimulation				
Occipital Nerve Stimulation				
Supraorbital Nerve and Occipital Nerve Combined Stimulation				
Auricular Nerve Stimulation				

Display This Question:

If Did you experience any physical or medical complications from the use of these procedures? [Severe Complications] (Count) >= 1

Carry Forward Selected Choices from "Did you experience any physical or medical complications from the use of these procedures?"

OP4A You indicated that you had severe complications

with: \${OP4/ChoiceGroup/SelectedChoicesForAnswer/3}. What kind of complications did you experience? Please include as much detail as possible. (For example, the procedure worked well but made me feel awful...)

IMPL An **internal** implant refers to any device implanted inside your skull cavity within your brain tissue. Please respond to the following statement: "I would be willing to consider an **internally** implantable device if it was shown to be safe and effective."

Very Unlikely

Unlikely

Somewhat Unlikely

Undecided

Somewhat Likely

Likely

Very Likely

IMPL2 An **external** implant refers to any device implanted outside the skull cavity in the tissue of the face or neck. Please respond to the following statement: "I would be willing to consider an **externally** implantable device if it was shown to be safe and effective."

Very Unlikely

Unlikely

Somewhat Unlikely

Undecided

Somewhat Likely

Likely

Very Likely

Q146 In the next sections, you will be asked to respond to two separate multiple choice questionnaires. Please please be sure to read the instructions carefully and answer each question as best you can. Click next to continue...

BDI Questionnaire 1: Instructions: This questionnaire consists of 21 groups of statements. Please read each group of statements carefully, and then pick out the **one statement** in each group that best describes the way you have been feeling during the **past two weeks, including today.** If several statements in the group seem to apply equally well, select the statement with the highest number for that group.

BDI1 Sadness

- 0. I do not feel sad. (0)
- 1. I feel sad much of the time.
- 2. I am sad all the time.
- 3. I am so sad or unhappy that I can't stand it.

BDI2 Pessimism.

- 0. I am not discouraged about my future. (0)
- 1. I feel more discouraged about my future than I used to be.
- 2. I do not expect things to work out for me.
- 3. I feel my future is hopeless and will only get worse.

BDI3 Past Failure.

- 0. I do not feel like a failure. (0)
- 1. I have failed more than I should have.
- 2. As I look back, I see a lot of failures.
- 3. I feel I am a total failure as a person.

BDI4 Loss of Pleasure.

- 0. I get as much pleasure as I ever did from the things I enjoy. (0)
- 1. I don't enjoy things as much as I used to.
- 2. I get very little pleasure from the things I used to enjoy.
- 3. I can't get any pleasure form the things I used to enjoy.

BDI5 Guilty Feelings.

- 0. I don't feel particularly guilty. (0)
- 1. I feel guilty over many things I have done or should have done.
- 2. I feel quite guilty most of the time.
- 3. I feel guilty all of the time.

BDI6 Punishment Feelings

- 0. I don't feel I am being punished. (0)
- 1. I feel I may be punished.
- 2. I expect to be punished.
- 3. I feel I am being punished.

BDI7 Self Dislike.

- 0. I feel the same about myself as I ever have. (0)
- 1. I have lost confidence in myself.
- 2. I am disappointed in myself.
- 3. I dislike myself.

BDI8 Self-Criticalness.

- 0. I don't criticize or blame myself more than usual. (0)
- 1. I am more critical of myself than I used to be.
- 2. I criticize myself for all of my faults.
- 3. I blame myself for everything bad that happens.

BDI9 Suicidal Thoughts or Wishes.

- 0. I don't have any thoughts of killing myself. (0)
- 1. I have thoughts of killing myself, but I would not carry them out.
- 2. I would like to kill myself.
- 3. I would kill myself if I had the chance.

BDI10 Crying.

- 0. I don't cry anymore than I used to. (0)
- 1. I cry more than I used to.
- 2. I cry over every little thing.
- 3. I feel like crying, but I can't

BDI11 Agitation.

- 0. I am no more restless or wound up than usual. (0)
- 1. I feel more restless or wound up than usual.
- 2. I am so restless or agitated that it's hard to stay still.
- 3. I am so restless or agitated that I have to keep moving or doing something.

BDI12 Loss of Interest.

- 0. I have not lost interest in other people or activities. (0)
- 1. I am less interested in other people or things than before.
- 2. I have lost many of my interests in other people or things.
- 3. It's hard to get interested in anything.

BDI13 Indecisiveness.

- 0. I make decisions about as well as ever. (0)
- 1. I find it more difficult to make decisions than usual.
- 2. I have much greater difficulty in making decisions than I used to.
- 3. I have trouble making any decisions.

BDI14 Worthlessness

- 0. I do not feel I am worthless. (0)
- 1. I don't consider myself as worthwhile and useful as I used to.
- 2. I feel more worthless as compared to other people.
- 3. I feel utterly worthless.

BDI15 Loss of Energy.

- 0. I have as much energy as ever. (0)
- 1. I have less energy than I used to have.
- 2. I don't have enough energy to do very much.
- 3. I don't have enough energy to do anything.

BDI16 Changes in Sleep Pattern.

- 0. I have not experience any change in my sleeping pattern. (0)
- 1a. I sleep somewhat more than usual.
- 1b. I sleep somewhat less than usual.
- 2a. I sleep a lot more than usual.
- 2b. I sleep a lot less than usual.
- 3a. I sleep most of the day.
- 3b. I wake up 1-2 hours early and can't get back to sleep.

BDI17 Irritability.

- 0. I am no more irritable than usual. (0)
- 1. I am more irritable than usual.
- 2. I am much more irritable than usual.
- 3. I am irritable all the time.

BDI18 Changes in Appetite.

- 0. I have not experienced any change in my appetite. (0)
- 1a. My appetite is somewhat less than usual.
- 1b. My appetite is somewhat more than usual.
- 2a. My appetite is much less than before.
- 2b. My appetite is much greater than usual.
- 3a. I have no appetite at all.
- 3b. I crave food all the time.

BDI19 Concentration.

- 0. I can concentrate as well as ever. (0)
- 1. I can't concentrate as well as usual.
- 2. It's hard to keep my mind on anything for very long.
- 3. I find I can't concentrate on anything.

BDI20 Tiredness or Fatigue.

- 0. I am no more tired or fatigued than usual. (0)
- 1. I get more tired or fatigued easily than usual.
- 2. I am too tired or fatigued to do a lot of the things I used to do.
- 3. I am too tired or fatigued to most of the things I used to do.

BDI21 Loss of Interest in Sex.

- 0. I have not noticed any recent change in my interested in sex. (0)
- 1. I am less interested in sex than I used to be.
- 2. I am much less interested in sex now.
- 3. I have lost interest in sex completely.

HDSQ Questionnaire 2: Instructions: On this questionnaire are groups of statements. Please read all of the statements in a given group. Then pick out the **one statement** in each group which describes you best for the past **TWO WEEKS**. If several statements in the group seem to apply equally well, choose the higher number. Do not choose more than one number for a given group of statements. **BE SURE TO READ ALL OF THE STATEMENTS IN EACH GROUP BEFORE MAKING YOUR CHOICE**.

1 1.

I have not stopped trying to get what I want. (0)

I have stopped trying to get what I want in some situations.

I have stopped trying to get what I want in most situations.

I have stopped trying to get what I want in all situations.

22.

I am not passive when it comes to getting what I want these days. (0)

In some situations I'm passive when it comes to getting what I want these days.

In most situations, I'm passive when it comes to getting what I want these days.

In all situations, I'm passive about getting what I want these days.

3 3.

I have not given up trying to accomplish what's important to me. (0)

I have given up trying to accomplish some of the things that are important to me.

I have given up trying to accomplish most things that are important to me.

I have given up trying to accomplish all things that are important to me.

4 4.

My motivation to get things done is as good as usual. (0) In some situations, my motivation to get things done is lower than usual. In most situations my motivation to get things done is lower than usual. In all situations, my motivation to get things done is lower than usual.

5 5.

I need little or no support from other people. (0) I need some support from other people. I need a lot of support from other people. I need total support from other people.

66.

I don't rely on other people t do things for me. (0) Sometimes these days I am overly dependent on other people. Most of the time these days I am overly dependent on other people. This days, I am always overly dependent on other people.

7 7.

These days I am not overly dependent on other people. (0) Sometimes these days, I am overly dependent on other people. Most of the time these days I am overly dependent on other people. These days I am always overly dependent on other people.

8 8.

I am not a burden other people. (0)
I am a burden to other people sometimes.
I am a burden to other people most of the time.
I am a burden to other people all of the time.

99.

I am not doing things in "slow motion" these days. (0) Sometimes, I do things in "slow motion" these days. Most of the time, I do things in "slow motion" these days. I always do things in "slow motion" these days.

10 10.

I do not walk around like a zombie these days. (0) Sometimes I walk around like a zombie these days. Most of the time I walk around like a zombie these days. I always walk around like a zombie these days.

11 11.

My speech is not slowed down. (0) My speech is somewhat slowed down. My speech is very slowed down. My speech is extremely slowed down.

12 12.

My thoughts are not slowed down. (0)

My thoughts are somewhat slowed down.

My thoughts are very slowed down.

My thoughts are extremely slowed down.

13 13.

My energy is not lower than usual. (0)

My energy is somewhat lower than usual.

My energy is much lower than usual.

My energy is extremely lower than usual.

14 14.

I can get things done as well as usual. (0)

In some situations I can't get things done as well as usual.

In most situations I can't get things done as well as usual.

In all situations I can't get things done as well as usual.

15 15.

I have as much energy as usual. (0)

In some situations I have less energy than usual.

In most situations I have less energy than usual.

In all situations I have less energy than usual.

16 16.

I do not get tired out more easily than usual. (0)

In some situations I get tired out more easily than usual.

In most situations I get tired out more easily than usual.

In all situations I get tired out more easily than usual.

17 17.

I enjoy things as much as usual. (0)

In some situations I don't enjoy things as much as usual.

In most situations I don't enjoy things as much as usual.

In all situations I don't enjoy things as much as usual.

18 18.

When doing things I normally enjoy (e.g. work; being with people) I have as much as fun as usual. (0)

When doing things I normally enjoy (e.g. work; being with people) I have somewhat less fun than usual.

When doing things I normally enjoy (e.g. work; being with people) I have much less fun than usual.

When doing things I normally enjoy (e.g. work; being with people) I don't have fun at all anymore.

19 19.

When it comes to things in life that count I am as interested as usual. (0)

When it comes to things in life that count I am somewhat less interested than usual.

When it comes to things in life that count I am much less interested than usual.

When it comes to things in life that count I don't have any interest at all anymore.

20 20.

I enjoy sex as much as usual. (0)
I enjoy sex somewhat less than usual.
I enjoy sex much less than usual.
I do not enjoy sex at all anymore.

21 21.

I do not have trouble falling asleep. (0)

It takes me somewhat longer to fall asleep than usual (i.e., up to one hour longer).

It takes me much longer to fall asleep than usual (i.e. up to 2 hours longer).

It takes me substantially longer to fall asleep than usual (i.e. more than 2 hours longer).

22 22.

I do not have trouble falling asleep at night. (0)

Sometimes I have trouble falling asleep at night.

Most of the time I have trouble falling asleep at night.

I always have trouble sleeping thought the night.

23 23.

I do not wake up early in the morning and have trouble falling back to sleep. (0) Some times I wake up early in the morning and have trouble falling back to sleep. Most of the time I wake up early in the morning and have trouble falling back to sleep. I always wake up early in the morning and have trouble falling back to sleep.

24 24.

I can fall asleep as well as usual. (0) Sometimes I have trouble falling asleep. Most of the time I have trouble falling asleep. I always have trouble falling asleep.

25 25.

My concentration is as good as usual. (0)

My concentration is somewhat less focused than usual.

My concentration is much less focused than usual.

I can hardly concentrate at all anymore.

26 26.

I can concentrate as well as usual. (0)

In some situations I can not concentrate as well.

In most situations I can not concentrate as well.

In all situations I can not concentrate as well.

27 27.

I do not brood about unpleasant events these days. (0) Sometimes I brood about unpleasant events these days. Most of the time I brood about unpleasant events these days. I always brood about unpleasant events these days.

28 28.

I am not distracted by unpleasant thoughts. (0) In some situations I am distracted by unpleasant thoughts. In most situations I am distracted by unpleasant thoughts. In all situations I am distracted by unpleasant thoughts.

29 29.

I do not have thoughts of killing myself. (0) Sometimes I have thoughts of killing myself. Most of the time I have thoughts of killing myself. I always have thoughts of killing myself.

30 30.

I am not having thoughts about suicide. (0) I am having thoughts about suicide but have not formulated a plan.

I am having thoughts about suicide and am considering possible ways of doing it.

I am having thoughts about suicide and have a definite plan.

31 31.

I am not having thoughts about suicide. (0)

I am having thoughts about suicide but have these thoughts completely under my control.

I am having thoughts about suicide but have these thoughts somewhat under my control.

I am having thoughts about suicide and have little or no control over these thoughts.

32 32.

I am not having impulses to kill myself. (0) In some situations I have impulses to kill myself. In most situations I have impulses to kill myself. In all situations I have impulses to kill myself.

REF How did you hear about this survey?

Advocacy Group email or newsletter Search Engine (Google, Bing, etc...) Social Media (Facebook, Twitter, LinkedIn etc...) Referred by Physician Website Other

EOS1 We appreciate you taking the time to complete this survey. Some of your responses may have been fairly extraordinary, and we may want to contact you later to get more detail. May we contact you in order to follow up on your responses?

Yes

No

EOS2 Thank you for your willingness to speak with us. What is your preferred contact method?

Phone

Email

Either one

EOS2A Please provide a valid email address.

EOS2B Please provide a valid phone number.

EOS3 In order to prevent us from contacting you at an inconvenient time, please tell us the time zone of your current residence? Time Zone Format - Coordinated Universal Time (UTC) UTC (+/-): Countries: Cities Select from list:

▼ UTC - 11:00 hrs: American Samoa - Tonga - Midway Islands ... UTC +/- 12:00 hrs: Eastern Russia - New Zealand - Fiji - Marshal Islands : International Date Line - Auckland (28)

EOS4 What time of day would you prefer to be contacted?

Morning (0800-1200 hours) Afternoon (1200-1700 hours) Evening (1700-2100 hours) Anytime is fine

HELP2 Thank you for participating in our survey. Before you leave, we want to remind you one last time about the increased risk of suicide associated with Cluster Headaches. If you are currently struggling with thoughts or feelings of suicide, please click on the below resources to find help and support in your area. International Lines Inside the US by State For facts, information, support and resources about cluster headache and suicide, click to download these attachments: Cluster Headache and Suicide 20 Facts About Cluster Headache Brochure Click the "next button" to submit your survey...