

BOB'S POCKET GUIDE TO CLUSTER HEADACHES

Opinions, Facts & Observations In The treatment of Cluster Headaches

Volume One - *Conventional Treatments*

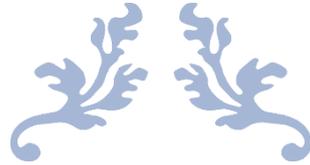
Volume Two - *Psychedelic Treatments*

Volume Three - *Living with Clusters*

Volume Four - *Research & the Future*

Volume Five - *The Gatekeepers*

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**Opinions, Facts & Observations In The treatment of
Cluster Headaches
Bob Wold**

Conventional Treatments

Volume - One



Cluster Headaches

Opening statement

This section contains additional comments on some prescription medications used to treat cluster headaches that are still in the realm of alternative treatments..

The following opinions are just that, my opinions based upon collecting many reports of their effectiveness and side effects. Also my personal experience in many cases (I tried over 70 of them in just the first 20 years of my cluster life.).

Many of these medications are used in combination with others and it's difficult sometimes to pinpoint what actually may be helping, if they are. One thing that seems common among typical cluster drug therapies is that if a single drug or combination is not working well enough, a new drug is often added without removing anything from the treatment plan. It may be that an antidepressant, or anti-convulsive is replaced by a different type. What happens if you are on a beta blocker and a calcium channel blocker and seem to be getting only a 20% relief in your cycle, your doctor may want to add an anti-seizure med to the cocktail. Both patient and doctor don't want to chance losing even that 20% relief and hope to build upon that by adding another type of medication.

This is how people end up getting on 6 or 7 different medications at the same time and still getting minimal relief.

When considering the risk versus reward of relief versus side effects, you need to consider the following. If a medication treats your clusters and gives you 80% relief and there are only a couple of minimal side effects, then it's easy to determine whether or not you want to continue on that drug regimen. But if you are on two or three or more medications and getting less than great results, it's more difficult to make those risk/reward decisions. Take a good look at the total side effects you are experiencing and also the possible long term effects, and compare the totality of the effects to the relief that you are getting. It may cause you enough concern to ask your doctor about switching things up a little.

Bob

Diagnosis and descriptions

Chronic vs. Episodic

The medical community and the public often get the facts wrong and if anyone needs to get it right, so we all get proper treatments, it's us.

The diagnostic criteria for chronic clusters vs. episodic have nothing to do with intensity or quantity of attacks. It's about distinctive cycles vs a never ending cycle.(other than an occasional break of a couple weeks.)

There are some distinct differences between them that distinguish the two conditions. Different treatments can work for one and not the other. Example: lithium can work for chronic clusters but is almost always useless for episodic. But the dose of lithium and many other drugs we use, far exceed normal doses used to treat what the medicine was developed to treat. Increased doses equal increased side effects.

Chronics often go through high and low periods which are sometimes connected to changes in season but these low periods are not the same as the breaks between cycles for episodics.

Between cycles for episodics their normal triggers such as alcohol will not trigger an attack for the most part. Triggers for chronics are always triggering for attacks whether they are in a high or low cycle.

That said, we are all different in some ways and we need to be careful about generalizing our symptoms vs generalizing cluster headache symptoms. Alcohol doesn't trigger attacks for everyone although it does for most. Strong odors like gasoline aren't triggers for everyone. Exertion can be a trigger for some people and a way to stop an attack for others.

Conventional Treatments

Our Motto: If you think you've tried everything and there are no new options, you're wrong.

There are many different options available today. Some of which you may have tried and others that are new. There is more research going on right now for cluster headaches than any time in history. Some brought to us by medical science, some still in the research stage that you can participate in, some that have been developed by what is known as "citizen science" (The cluster headache patient community itself) and some being developed by medical device manufacturers. New options, some coming out of labs, some from nature, some from medical engineers.

Devices

1. GammaCore Device

This handheld device that is produced by a company called Electrocore has been available in various parts of Europe for several years prior to being approved here in the states.. Results vary (just like everything else) but is worth looking at as a treatment. The device is placed on the front side of your neck along the Vagus nerve. It's used abortively and also as a preventive that shows results that can improve over time as its used. There is a new device coming from this company in 2025.

Prescription Meds and OTC options

Comments:

Comments on some common prescription medications used to treat cluster headaches.

The following opinions are just that, my opinions based upon collecting many reports of their effectiveness and side effects. Also my personal experience in many cases

Many of these medications are used in combination with others and it's difficult sometimes to pinpoint what actually may be helping, if they are. One thing that seems common among typical cluster drug therapies is that if a single drug or combination is not working well enough, a new drug is added without removing anything from the treatment plan. It may be that an anti depressant, or anti convulsive is replaced by a different type. What happens if you are on a beta blocker and a calcium channel blocker and seem to be getting only a 20% relief in your cycle, your doctor may want to add an anti seizure med to the cocktail. Both patient and doctor don't want to chance losing even that 20% relief and hope to build upon that by adding another type of medication.

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Currently Available Treatments

Over the counter & Doctor supervised

There are additional OTC treatments also listed in the Psychedelic Volume

D-3 Regimen

Yes, this paragraph is also found in the psychedelic treatment volume.

Even vitamin treatments can cause issues if not carefully added to your body. An example that many cluster patients have is that many of us use magnesium and sometimes in pretty large doses. You should be aware though that if you use magnesium for extended periods and especially at large doses, you should also be taking an equal dose of calcium. So, talk to your doctors about anything you will be putting into your body. (Including psychedelics. They are perfectly allowed by law to discuss psychedelics and it's been brought up as an ethical issue if they refuse to discuss them with you. They can't prescribe them for you but they can discuss their opinions and especially share any safety issues you should be aware of based upon your own health and possible contraindicated medications. If you need to titrate off a medication to give psychedelics the best chance of working, they should be consulted on how best to work your way off the medication in question.

Some people have had great and lasting results with using the D-3 Regimen. Others have partial results and can make other treatments more effective. Others have given it a try with not very effective results. This is like most other things, there are little tweaks that can make it more successful for some. This is like just about everything else in that everyone is different and there will usually be some adjustments that make it better for each individual.

Prescription Medicines and Treatments

Oxygen

So important that it has it's own section here.

The first and most effective abortive treatment that everyone should try first, is high flow oxygen. It should be the first words out of your doctor's mouth following the statement diagnosing that you have cluster headaches.

High Flow Oxygen for Treating Cluster Headaches

When you have been diagnosed with cluster headaches and after the doctor has explained the basics that come with the condition, the first thing that he or she should say is, *“and I am prescribing high flow oxygen as your front line acute treatment.”*

Oxygen has been an extremely effective and safe treatment for cluster headaches for over 50 years. That said, there is often a disconnect between the effectiveness of this treatment and both getting it prescribed and getting it covered by insurance.

People that routinely have their cluster attacks last an hour or more, are often able to treat and end an attack in ten minutes. Anyone suffering through an attack can attest to how much that shortened time span can mean.

There are some simple guidelines that need to be followed to be able to get the best results and little details that aren't followed can mean the difference between success and the failure of the treatment.

The prescription should be written to include the following details:

100% high flow oxygen for cluster headaches

12-15 LPM flow rate

Supply with non-rebreather mask

When you have the prescription in hand, google a local medical supply house that delivers medical grade oxygen. They will need to prescription to fill your request.

If your insurance company doesn't want to cover the oxygen, you should still request the prescription and ask your doctor to help you get them to cover it.

The larger supply houses will know what is usually sent for cluster patients but you may need to do some work getting what you need.

Order both “E” tanks and larger tanks, either “M” or “H.”

E tanks are portable and will allow you to not have to worry about having to miss birthday parties or the Sunday Football game with the guys.

The larger H or M tanks aren't portable but can treat many more attacks.

The number of attacks per month you are expecting will determine the number and sizes of the tanks you'll need delivered.

The E tanks will also require a different type of regulator than the larger tanks. Your supplier will know to bring different regulators.

There are a few basics in using the oxygen set up as a treatment once you have it.

Set the regulator to give you enough oxygen so that the reservoir bag does not completely deflate when you inhale. Lung capacity and rate of breathing will determine how high you need to set the flow.

Cut the rubber strap off the mask so that you don't fall asleep with the mask on. The attacks are so draining that its very common to doze off once the pain has receded.

Start on the oxygen as soon as you feel the attack beginning. Do not wait.

Breath deeply and quickly, emptying your lungs on exhale.

Stay on the oxygen for an extra few minutes after the attack has ended. This will help avoid a return of the attack.

Once you have the initial set up, there are a few tricks that can really boost the effectiveness.

If the 15 LPM regulators aren't giving you enough oxygen you can order regulators online that will go up to 25 LPM or a demand valve. The demand valve can be worth the extra money because it eliminates any wasted oxygen.

There is a specially designed mask just for cluster headaches that makes a big difference. If you don't want to order a new mask, you can tape off the holes in the sides of the non-rebreather mask that came with your set up. The quickest way to end an attack is not allowing any room air into the mask.

If you need to pace during the attack, tell the supplier that you need a 30 foot airline.

If you have cluster headaches, oxygen can be your best friend. If you need to fight for the prescription or your insurance company, it is a fight worth fighting.

If you can't get a prescription or if your insurance company won't cover it, there is a DIY work around using welding oxygen.

If you haven't tried it with the proper mask, at a flow of at least 15LPM, and stayed on it until the cluster ended, then you really haven't given it a fair shot.

If 15LPM doesn't do it for you, you can try a 25LPM regulator or a demand valve that allows you to breath as deeply and as quickly as possible without emptying the bag.

If you are using a mask that has holes in it, tape them off. Do yourself a favor and order a cluster mask asap.

You can order the best available mask here:

<http://www.clusterheadaches.com/ccp8/index.php?app=ecom&ns=prodshow&ref=clustero2kit>

Besides the mask you need a regulator that will go to at least 15LPM if not a 25LPM regulator. Your doc can and should write a script for a 15LPM regulator and your O2 supplier should be able to supply one to you for any size tank they send you.

If the 15LPM isn't supplying enough O2 that you can breath as quickly and deeply as possible, without the bag emptying, people have modified their set up by removing the existing small bag and attaching a plastic garbage bag. Allow the larger bag to fill up early on and you should be able to provide yourself with enough O2 to keep up with your breathing.

If not both can be found on Ebay.

A lot of O2 info can be found on our website. www.clusterbusters.org

Click on the oxygen tab in the drop down menus.

Also, although since 2015-16 most people are finding best results using 15LPM as a minimum and many others now using 25LPM, the following abstract shows what people were using in 2008. Something you can print out and take to your doctor. If they are still prescribing based upon 1960 recommendations, they should at least catch up to 2008/2009.

<http://www.clusterheadaches.com/O2/Rozen%20and%20Fishman%20final%20r4%20CH%20survey%20O2%20focused%20abstract%20IHC%202009.pdf>

If you are in the UK, sorting out the oxygen issues with NHS is best done by contacting OUCH UK first. You can also contact Ainslie Course from the online support groups we offer on the website.

Oxygen as an acute treatment for cluster headaches

We encounter many cluster patients that come to us stating that they had tried oxygen and it didn't work for them in the past. When we work with them, they almost always are able to make it the most effective acute treatment they have. Once its working for them, their tanks and set ups are the most valued asset. That said, high flow oxygen does not work well for some patients, sorry to say but being honest. Also though, as discussed elsewhere, just because it didn't work last year, or hasn't worked for the last 5 years, it can become a useful tool again at some point and well worth checking out occasionally.

There are several long used oxygen protocols that are prescribed by doctors when they write a prescription. One of the oldest protocols calls for a flow rate of 7-10 LPM with a non-rebreather mask, for 15 minutes.

Some doctors continue to use this out of date protocol. If they continue to work with the patient and increase the flow rates they are able to sometimes come to a rate that is successful. Unfortunately, the problem with this protocol is that many patients start and end with trying 7 LPM (Liters per minute) and think that O₂ doesn't work for them. They then go years or a lifetime never giving O₂ a chance again.

We at Clusterbusters recommend prescriptions be written for a minimum of 12-15LPM. Most medical supply companies that supply home oxygen do not have regulators that go higher than 15LPM.

If this regulator does not supply a large enough flow rate for very effective treatment, ending an attack in 15 minutes or less, we suggest the patient locate a new regulator online and purchase this regulator. Order one that fits your tanks supplied by your O₂ supplier. The E tanks use a different regulator than the M tanks or larger.

In addition, for best results, rather than using a standard non-rebreather mask, we suggest patients order a new mask online. These are available at clusterheadaches.com for a reasonable cost. These masks do not have any vents on the sides and provide an airtight, comfortable fit.

Best breathing techniques can vary but each individual should test out different procedures until they discover which one is best for them.

1. Always keep flow rate high enough to make sure the attached bag never deflates completely but low enough to not waste extra oxygen.

2. It's best to use a regulator that goes up to 25LPM or use what is called a demand valve. This type of valve does not use a bag to collect the oxygen but allows direct flow from the tank for as deeply and quickly you want to breathe.

3. Sit up straight if you are using in a seated position. This allows your lungs to expand fully and inhale as much fresh O₂ as possible.

4. Breathing can be done in two or more ways. Some people prefer to breath a bit slower to help relax and to help stay calm during the attack. Still breath deeply and exhale completely. Others have the best results by breathing as quickly as possible, nearing hyperventilation. In this case its still important to breath deeply and exhaling completely.

5. There are many theories regarding what the process is that aborts the attack. One that seems somewhat likely is not the increase in blood/oxygen ratio as this is very difficult to make much of a change no matter how much you inhale, but the elimination of carbon dioxide by flushing it out with pure oxygen.

6. If you still have not completely eliminated the attack after 15 minutes, it is still safe to stay on the oxygen until the attack ends. There is no fear of side effects or any type of damage caused by

staying on O2 for an extended period. Fighter pilots stay on pure O2 for 8 or more hours without any issues.

7. If you have problems with attacks seeming to occur soon after aborting an attack with O2, you should be sure to stay on the O2 for a few minutes after the pain is completely gone.

Additional information can be found on our website www.clusterbusters.org in the resources section. Included are ordering instructions for regulators as well as finding the proper O2 mask.

Some miscellaneous tips & notes on conventional prescription medications.

When discussing any medications, whether they are prescription, over the counter or natural remedies, it is important to remember that old adage we've all heard before, "everyone is different."

Some people have much more severe cluster cycles and attacks than others. Just as some of our attacks are 10s and some are 2s, some people have cycles that are 2s and some have cycles that are 10s. One thing no one should ever feel obliged to do is either justify their pain levels or minimize the suffering they endure. No comparing is allowed. You have what you have and others have what THEY have.

Some people are able to treat their cycles with low doses of medications and others need much higher doses before getting to a therapeutic level. This does not seem to have any correlation with the length or severity of their cycle. Some people can stop a cycle that that is very severe with a low dose of a preventive. Others have much less severe cycles but need very high doses of anything to get any relief.

Abortives - Acute Treatments

A. Imitrex and the other triptans

Personally I am not a fan of Imitrex and have mixed feelings. It's a bit like having a relative you can't stand but is the only one that will watch your dog for a week while you go on vacation. Yes, it is effective and there is no doubt that it has saved many lives over the years. In the throws of an attack and having an injection sitting there offering relief, it's difficult to leave unused.

On the other hand, as it has been proven through studies that it can make cycles last longer and add to the frequency and intensity of attacks.

See:

[http://www.clusterheadaches.com/cb/yabbfiles/Attachments/Subcutaneous Sumatriptan and rebounds.pdf](http://www.clusterheadaches.com/cb/yabbfiles/Attachments/Subcutaneous_Sumatriptan_and_rebounds.pdf)

But if that is your choice of abortives, there are things that can make things a little better and at the same time a little safer.

Standard injections of Imitrex work the best for cluster headaches. The pills are about useless for aborting an attack as they take too long to get into your system. If you are going to use these injections, the standard dose in the injector is 6mg. It has been found that 2mg of the injections are enough to abort a cluster attack. So you are able to actually treat three times as many attacks with however many injections you are prescribed or your insurance will cover.

There are two ways around this. One is to bastardize the injector and use a Q-tip as a plunger and just inject 1/3 of the liquid at a time. There are instructions for this on You Tube as well as more detailed info on the cluster site: clusterheadaches dot com.

The other way is to ask your doctor to prescribe vials of Imitrex. You can get a small vial and empty syringes and you can measure out 2mg doses that way.

B. Opiates

For every 1 person that these help for any extended period of time, there are 99 that range from no relief to devastating results. They do not work fast enough to treat an attack. Taking them on a round-the-clock basis provides very little relief and will most likely end up as first building a tolerance to them and ending up addicted. They will also block many other treatments that you may want to try along the way.

They can also lead to rebound headaches that make everything worse in the long run. Not only can they trigger more cluster attacks, they may end up adding Medication Overuse Headaches, so in between your clusters, you have another headache disorder to deal with. You can forget any clear thinking in between your cluster attacks and can lead to a spiraling downward.

If you get referred to a pain management clinic, they will try to treat your clusters with pain killers of some sort and this rarely helps, even in the short term. Please be careful. Yes, they have helped some people, I get it.

C, Nerve Blocks (Transitional)

Nerve blocks that may be offered may contain steroids but not all do. These can possibly help if done properly and are usually most effective when used in conjunction with other therapies. The blocks will wear off. Specialists are getting better at these blocks as time goes on. Find one that has experience blocking for clusters.

D. DHE - 45

Dihydroergotamine is in a group of drugs called ergot alkaloids. It works by narrowing the blood vessels around the brain and affects blood flow patterns that are associated with certain types of headaches. Ergots have long been used to treat headaches, including clusters.

It comes in three forms. You can get prescribed injections that come in a vial and then you draw the solution into syringes. They aren't prefilled like Imitrex.

There is also a new auto injector coming out in 2025

It also is available in a nasal spray form and is called Migranal. See below at D.1.

The nice thing about these products is that they usually provide longer lasting relief than the triptans. There are side effects that need to be discussed with your doctor prior to using. The bad thing about them is that for some reason, even though they've been around for many years, the prices if these have skyrocketed over the last couple of years. (See additional info further down in this document)

Thirdly, some headache clinics and specialists offer an in patient IV treatment with DHE. This is often suggested to break a particularly long or bad cycle. It changes a bit from clinic to clinic but is most often a 3 to 5 day hospital stay. It often will break the cycle while you are on the IV and sometimes a little extended relief. In almost every case, the cycle will return although there is a chance it can end an episodic cycle early.

D.1. Migranal (DHE) Spray

This is available as a generic and has been around for many years. It has become very expensive (as have many generics for some reason). There are also shortages of it from time to time. Because of the high prices and reimbursement schedules, some pharmacies may not carry it. Many doctors, including headache specialists, won't prescribe it for clusters due to its ergotamine base structure. There are many co-morbidities that can make DHE and ergotamines not as safe as sumatriptans, for some people. Discuss all your health issues with your doctor prior to using.

Again, it is an Ergot derivative so all the warnings that go with ergotamines should be followed.

What is good about this versus the triptans is that this spray can work better than the triptan sprays and also, it can give you much longer pain free periods than the triptans. An Imitrex shot may only help one attack during the day and you may still have more attacks to get through that day. Its much more likely that if this helps you, it can give you 24 hours of relief. So if you're used to having 6 attacks a day, it can eliminate all of them, unlike Imitrex.

E. Lidocaine drops.

You need a prescription for this but it is pretty cheap and can help sometimes. For clusters you need a 4% solution and it is applied using an eyedropper. The instructions for its use can be found on our website and it is very important that it is done properly or it won't work.

It is a way to apply a treatment similar to an SPG block that you can administer by yourself.

It's an abortive in the form of an anesthesia that can sometimes help you get some sleep. Lidocaine sprays do not help. Don't waste your time.

The trick is to take a dropper full, lay down on your back, on your bed, with your head over the edge, tilted backward and downward, head tilted about 30 degrees toward the side of your cluster, and insert the liquid. You want to bath the nerve ganglion located in the backside of your sinus cavity with the liquid.

F. Ketamine Nasal Spray

Prescription only

Yes, Ketamine is listed here because it is not a classic psychedelic and it is used by some doctors. It can be prescribed, and is prescribed.

This one is in the fairly early stages of testing although some headache specialists have been prescribing it now for a few years. It has shown some signs of success for some people but its use needs to be monitored closely by the prescribing physician. There are some possible serious side effects if used improperly. If there is one important thing to remember about this drug, it is that it should be used "sparingly" and this can lead people with clusters down that slippery slope we often find ourselves. Clusters themselves don't come upon us in a sparingly fashion and when we find something that works, it's difficult not to use it as often as the attacks command.

G. Ketamine topical cream

Prescription only

This is available through compounding pharmacies and is usually rubbed into the area where the nerve ganglion is located on the back of the neck. Often described as the cluster lump.

H. Ketamine Infusion - Inpatient

Usually done only as an in-patient treatment, this is now being offered by some clinics and physicians as an out-patient option. Clinics are still determining the best dosing program and length of stays and number of treatments. Check with the clinic about their success rates before making any decisions on entering the program. There is definitely a difference with in-patient programs between cluster and migraine ketamine treatment plans and programs with many designed for treating more mental health related issues. Be sure to determine if the program you are considering is well trained and program specific for cluster headaches.

See Addendum One for an expanded discussion on Ketamine if this topic interests you.

I. DMT (see the Psychedelic Volume Two)

Preventives

1. CGRP's - Emgality _ Eli Lilly

This is a rather new prescription treatment that was developed specifically for cluster headaches and not a migraine treatment hand-me-down. The molecule involved is the same one used for migraine but because of clinical studies done to test and develop specifically for cluster patients it was determined that cluster patients needed three times the amount of medication required to treat migraine.

This is a once every 28 day injection which is a total of three injections per treatment. This change in dosage is extremely important and you need to make sure that your doctor is prescribing the "cluster headache" dose (three injectors) and not the one injector dose for migraine.

This has proved very effective for many cluster patients. It often takes until the 2nd set of injections to start to show effective results. Don't give up on it early. It's also know to make treatments like high flow oxygen more effective while on the Emgality. So, if O2 wasn't working well before, be sure to give it another try.

More detailed information can be found on our website as well the Eli Lilly website. You may need to work on your insurance company to get it covered. It's something that your doctor may be able (or needed) to help with getting coverage.

2. Anti Convulsants:

Topamax.

Often prescribed, rarely successful at a dose low enough to lead a normal life IMHO. Some people are able to tolerate it without too much of a problem but many end up agreeing with it's nickname of Dopymax. You need to start out at a low dose (<100mg) and slowly titrate upwards to a therapeutic dose. I have seen some people go as high as 400mg per day and not only forget where they left their car keys, but forget where they left their car.

Tegretol.

This is rarely prescribed anymore and has been replaced by newer drugs that have fewer side effects. It'll depend upon how old the book is that your doctor is using to find treatments.

Neurontin.

This one was starting to be prescribed very often when it was being touted as a cure-all for everything from arthritis to stubbed toes. Once again it usually ends up being prescribed at very high doses because you'll start at a reasonable dose and then keep upping the dose in hopes that more will work better. Odds are it won't. It's also prescribed along with other drugs as a cocktail for clusters.

3. Calcium Channel Blockers

Verapamil.

The most often prescribed preventive and the most effective. This is another one that people start out with relatively low doses and continue to build until you reach a therapeutic dose. Many people end up as high as 1200mg. It is taken every day and there are some side effects that need to be considered. If you have low blood pressure you'll either have to avoid this one or be very careful.

You'll also need to find ways of countering the constipation. This is one of the medications that "can" produce fewer side effects but even this one can cause problems. You need to watch your blood pressure. Some people can get some relief at lower doses like 120mg or 240mg per day. Others have been known to require up to 1200mg for some relief. But the higher the dose the worse the side effects usually. Some people are able to tolerate a therapeutic dose without bad side effects but others have bad issues. One of the worst to deal with on a daily basis can be the constipation that comes with this medication. If you're going to be on it long term, you'll most likely need to find a way to fight that.

There are also a couple of serious heart complications that can arise and EKG testing is essential in keeping ahead of any serious health issues. If your doctor isn't ordering regular EKG's, demand them or demand to get off this med.

There is also further discussion on Verapamil on the Psychedelic Volume Two (as are discussions on other prescription meds in relation to their use during trying psychedelic methods).

4. Anti Depressants:

SSRI's

There is a long list of AD's that are used and they may help more with the depression that can set in with clusters than helping with the clusters themselves. Some people, like with most everything, can see some help with these but again, they are always prescribed as part of a cluster cocktail making it impossible to know what, if anything, is helping at all. Your doctor is most likely prescribing these looking to specifically treat and help your cluster headaches as there is some indications that these med's can help with pain transmission. So, don't be offended, thinking the doc thinks it's all in your head and treating your mental health. Most of them know that the best way to treat any mental health conditions you may or may not have, will be best treated by treating the pain of clusters. "If you want me less depressed doc, fix my pain."

5. Lithium:

Lithium has long been used as a preventive treatment for clusters. It is pretty much ineffective for episodic clusters but has been effective for some people that are chronic. Dosages are fairly high and it will take some time to get used to it and get past a lot of the side effects but these side effects can level off after a while. It is a very powerful drug and side effects can be substantial.

6. In-Patient treatments

DHE Infusion

This treatment is done as an in-patient treatment plan and can last 4-5 days in most cases. It consists of being hooked up to an IV that drips DHE into your bloodstream. It's most often prescribed and suggested for people that are stuck in a very bad and prolonged cycle and it hopes to break the cycle. In the very least, it's hoped to at minimum give you a 4-5 days break from attacks. The time that it extends past ending the treatment and heading home, varies from patient to patient. Once again, it can also help make other treatments more effective once you get home.

Ketamine Infusion (See Addendum One below for details)

Anti-Histamine Infusion

This treatment is possibly still only used at the Diamond Headache Clinic.

It is an in-patient treatment that consists of a near two week long stay at their facility in the hospital they are affiliated with and usually has their own wing.

You go through about 24 bags of histamine solution. The purpose is to keep a steady flow of low dose histamine running through your system to build up an immunity to the histamine that is naturally produced by your body. Histamine desensitization.

It can break a cycle and has been successful for many cluster patients over the years. Diamond developed this treatment protocol. They are located in Chicago.

Transitional treatments

These treatments are used in an attempt to slow down or stop the attacks long enough for preventative treatments to start taking effect. Many of them need to build up to a therapeutic level in your system before they will start working. These transitional treatments are not meant to be taken long term.

A.Prednisone & Steroids

These are normally prescribed as interim treatments to try to cool off a cycle while other medications can be built up in your system to a therapeutic level.

Sometimes for episodics a short burst can hold down the attacks until the cycle comes to its natural end.

I understand the desperation people can feel at the height of a brutal cycle and how these types of medications can help get you through a particularly bad time in your life.

The doses used to treat clusters are very high on the scale of dose amounts for such powerful drugs. People that require them on an ongoing basis for such things as chronic respiratory disease may be prescribed 5mg per day. Cluster people are usually starting at 60mg or 80mg. Side effects at these doses can be extreme. These aren't limited to physical effects. You may find yourself in fits of rage. You may find yourself not only wanting to eat everything in the refrigerator, but you may want to actually eat the fridge itself.

Long term effects if you use these treatments too many times can include severe joint issues due

to Avascular Necrosis (bone death). Your soft tissue organs are also not safe long term. Never stop these treatments cold turkey. You must slowly lower the dose as you end the prescription.

A warning also found on the Psychedelic Volume Two.

Found in both volumes as it is very important.

The adrenal glands, specifically, the adrenal cortex, are the organs that reduce or stop producing their natural steroid hormone, cortisol, when someone takes prednisone for a long time. Prednisone is a synthetic corticosteroid, very similar to cortisol. When you take it over a long period (especially at high doses), your body sees there's already plenty of steroid around, so the brain reduces its signal to the adrenal glands to make cortisol. That signal is a hormone called ACTH (Adrenocorticotropic Hormone), which comes from the pituitary gland in the brain.

If you suddenly stop taking prednisone after long-term use, your body might not be able to make **enough natural cortisol** right away, because the adrenal glands have gone "asleep" from disuse. This can lead to a serious and **potentially life-threatening** condition called **adrenal insufficiency**.

An **ACTH stimulation test** (often done using a synthetic version called **cosyntropin**) is used to check how well your adrenal glands respond to ACTH.

Here's why it's done:

To **test adrenal function** after long-term steroid use. (80mg tapered down over time is long term use.)

To see **if your adrenal glands have "woken up"** and can make cortisol on their own again.

To help decide **whether it's safe to stop prednisone** or reduce the dose.

During the test, they give you an ACTH shot and then check your cortisol levels at specific time intervals (like 30 and 60 minutes later). If your cortisol rises properly, your adrenal glands are functioning. If not, they're still suppressed.

Unfortunately I have spoken with many clusterheads over the years that had been on long term use of prednisone and had a terrible time after getting off of it, and had never been directed by their doctors to have this ACTH shot and testing. If you've had this happen to you in the past, you should confront your doctor if it's the same doctor that last prescribed your prednisone about this or if it's a new doctor, make your experience known if they want to prescribe prednisone for you.

There will be additional documents provided with this handbook that describes additional information that explains why we are all different. Why we all need to find the treatment plan that best fits you as an individual and **what this process entails for you**.

Links to additional information on the above topics as well as additional research and information can be found on the Clusterbusters website.

Things that don't work so don't bother.

When I say they don't work, here is my explanation. Some people may get short term relief and others may seem to get longer term results. Most or all of this can be easily attributed to a few things. There is a placebo effect, even with cluster headaches. Yes it may seem hard to believe but it is true and has been proven through numerous studies.

There is also the confusion caused by the very nature of cluster headaches. Episodics go in and out of cycle, making it difficult sometimes to determine if the relief is from a medication or from a natural cessation of the cycle. With chronics, there are also high and low periods within the year. Most often caused more by seasonal changes than medication effectiveness.

When people say that something was working and then stopped, this change is likely to have been caused by either the fact that the medication was never working and it was a natural change in your cycle, the placebo effect wore off, or the medication had thrown your system off its natural course for a short period of time and your brain found a way to get back on it's malfunctioning course.

1. Inadequate Oxygen.

Using a nose canula and a concentrator does not work. It won't work to abort an attack and it won't work if you're thinking that if you hook yourself up and try to use it during the night to try to get sleep. The high flow oxygen treatment does not work by raising your blood/oxygen levels. Everyone's is about 98% as it is, unless you have another serious problem. Details on possible reasons for it working or not working vary from expert to expert.

2. Daith Piercings.

Yes, this was all the rage for a while.

You can pierce your ears or any other part of your body and you will not affect the cluster headaches in any way. This is still on my list only because it is a perfect example of the sorts of things that pop up regularly as we all try everything we think may help or hear that helps others. This one was all the rage for a while. I believe it started with the migraine community as they also go on deep searches for help.

3. Massage Therapy

This is not going to help your clusters in any way and could trigger an attack.

What it can do is help release some of the tension in your shoulders and neck area and help you feel a little better. It's also possible for that short time alone taking care of yourself to help you deal

with the mental stress. You again have to be careful though about the stress reliever being a trigger. There seems to be a couple hundred different types of massage therapies. They will all have the same results. This includes Shiatsu, Reflexology, Reiki and Craniosacral therapy. This one especially, Craniosacral therapy is actually known to trigger attacks pretty constantly. If they help get you through the mental end of this condition, that's fine. In my opinion, donating that hour of your time, working in a soup kitchen for the poor will help as much or more, and you'll save a hundred dollars. But there isn't a price for getting an hour break and relieving all the tension that clusters can bring.

4. Acupuncture & Acupressure

Don't, just don't bother. (yes, just my opinion)

5. Biofeedback & meditation

Again these relaxation techniques may help with some of the stress involved in clusters but they may be a trigger more often than not. See massage therapy.

6. Chiropractic

Don't, just don't bother. For those that appreciate this treatment, it can be helpful in loosening up those tight neck and shoulder muscles, and we all know how tight those can get during a cycle. Probably best choice would be to set up an appointment with the massage therapist in the Chiropractic office and get the help they can provide and skip the bone cracker. (Just my opinion. One size does not fit all.)

7. Electronic pulse devices

Example: TENS units.

Many people have tried them over the years. Myself included. I would put the pads on the back of my neck and increased turning the voltage up to maximum and my and my neck would convulse and then lock in place so that I could not move, and the clusters would continue unabated. I resorted several times to do what they warned me not to do as it would be dangerous, and put the pads on my temples and the electric shock would move across my brain from temple to temple. The clusters continued unabated.

Never worked for me or anyone else that reported trying these devices.

This is different than the treatments that are provided with the devices such as Gamma Core that works on the Vagus nerve in the neck.

Addendum One

Ketamine Treatments (expanded version and discussion)

This starts with a description with their migraine treatment plan but be patient, that part explains all the reasoning and how this info related directly to the cluster treatment plan.

Ketamine at Jefferson

By Katie M. Golden & Numerous contributors

Thomas Jefferson University Headache Center in Philadelphia, PA has a five-day inpatient ketamine program for those with chronic migraine. Ketamine is a general anesthetic medication usually used in emergency patients, in surgical procedures, as well as in veterinary medicine. Its use has increased widely in recent years as a promising treatment for depression, PTSD, and pain management.

At a therapeutic dose, Jefferson has found ketamine can reduce the severity and frequency of migraine attacks. Everyone responds differently and expectations should be managed. Sometimes the positive effects are not felt until days or weeks after discharge, while others may not respond until after two or three hospitalizations. For some, a challenging migraine cycle is aborted during their first ketamine treatment!

I (Katie) have been living with chronic, intractable migraine since 2011. The head pain and other associated symptoms of a migraine attack are with me all day, every day. Since 2014, I have personally gone to Jefferson for their inpatient ketamine treatment at least once or twice a year. I notice a significant decrease in my daily pain average within two to four weeks. Around the six-month mark, I can feel the effects starting to wear off. Besides psilocybin, it has been the most effective tool to manage my chronic migraine disease.

Here are some important things you should know about being on a constant IV drip of ketamine for five days in a hospital setting:

You do not have to stop taking any medications, as they will be administered during your stay. Based on your treatment plan, you may be given additional IV medications such as DHE, Zofran, Benadryl, Compazine, and Magnesium.

The pain management team works with the attending headache specialist to administer ketamine. The dose you receive is based on your weight - approximately 1 ml per kg. (For example, 130 lbs = 60 kg. So 60 ml of ketamine is typically the highest dose you would

receive). However, the ketamine is titrated over the first two to even three days based on how well the medication is tolerated. It is increased by 5 ml - 10 ml at a time.

As the dose of ketamine increases, there are multiple side effects you could encounter. Ketamine is considered a synthetic hallucinogen and a dissociative drug. In my first inpatient hospitalization, the nurse said the first 5 ml increment of ketamine would feel like I've had a martini on an empty stomach. At 10 ml it would feel like I've had three martinis, and as it increases I'll start to feel disassociated - like I'm floating above my body.

After day one, you'll be considered a fall risk. You'll have to call the nurse to help you to and from the bathroom. It's a pain, but it's for your own good. If you can, try hard to take a walk around the halls daily with a nurse.

You may experience vivid dreams, double vision, feeling like you are floating above your body, difficulty speaking, visual disturbances, anxiety or paranoia. If any of these symptoms are too difficult to handle, tell your nurse immediately as the amount of ketamine can be turned down and/or a dose of Ativan (or equivalent) can be administered to help counteract what you're feeling.

You will receive a prescription of compounded nasal spray to use at home after being discharged. This helps me when my pain starts to spike. Just be very careful of how much, when and where you use it!

Other helpful tips for having the best experience while you trip on ketamine for five days:

Go in with a positive attitude. Be open to the experience. Communicate all your feelings and questions with your care team.

You'll have your own room and bathroom. The set and setting of being on any hallucinogen is very important. I bring personal items to dress up the room and feel more at home. I have music on, I use essential oils, I bring a blanket from home, I have adult coloring with me, and I bring my comfiest clothes.

Stay off social media! Honestly, leave your computer at home.

You're never too old to need your mom. Typically, my mom and a friend split staying with me during the day. My memory is hindered and I forget a lot, so it's nice to have someone with you who can take notes or advocate on your behalf.

It takes a few weeks after being discharged to really feel the effects. So don't be disappointed if you're struggling when you go home. It will get better.

Jefferson recently started a cluster headache specific treatment program. Here are the facts concerning cluster treatments vs. Migraine

Specifics follow

1. What are some specifics on the treatment protocol for clusters.

It's really not fundamentally different from how we use it in other headache syndromes. For the inpatient infusion, the pain management service has a dosing schedule that is weight based. Usually the infusion starts at 10 mg/hr and then is adjusted up or down by the pain team, sometimes a few times in a day, depending on how well it's working and how well it's tolerated. The max dose is 1 mg/kg/hr. This is still considered a subanesthetic dose.

The infusion is for a maximum of 5 days. We check baseline liver enzymes and monitor these through the stay. With the nasal spray, we all have our nuances with how we counsel patients to use it. My personal practice is to have them start with 1 spray at a time every 15 minutes until there is relief or mild inebriation. From there, once they have a sense of how the medication affects them, they may increase to as many as 3 sprays in each nostril every 5 minutes. We generally set a limit on use to 2-3 days/week and 20 sprays per day.

Each spray has 10 mg of ketamine in most cases. Sometimes we write it for a concentration to deliver 15 mg per spray, but you can't get much more than that to stay in solution. In all cases, we of course caution patients about the mind altering effects and all the safety concerns that go along with such a controlled substance. Especially when inpatient, we strongly advise that they don't make any financial decisions, conduct any business, use social media, or talk on the phone with people who don't know them well and don't understand the effects of ketamine.

At home, they have to be responsible with it, both in terms of their own personal use and keeping it out of the hands of others. All patients must sign a treatment consent before getting ketamine in either form. It's worth noting that the results an individual gets from the IV vs the nasal spray can be very different and are not predictive of each other.

2. If there are differences between treating a chronic patient vs episodic

Not fundamentally, but mostly it's those with chronic cluster headache who need this level of treatment.

3. What is allowed as acute treatments during the protocol?

In the hospital it's basically just the ketamine and oxygen. Outside of the hospital, a triptan or DHE is usually ok in addition, with the caution that blood pressure could become elevated. We would not recommend ketamine in combination with any psychedelics.

4. How quickly (or long) the patient can see positive results. Or is this very different from patient to patient.

Yes, it varies quite a bit, from zero benefit to significant, rapid, lasting improvement. I think we have some patients who were chronic that reverted to (or finally got to) an episodic state from the inpatient treatment. It doesn't take long to determine if the nasal spray works acutely at home. I personally have not had any patients try ketamine at home as a bridge to shorten a cycle, but others may have.

5. A few additional comments from the doctors:

If we see a patient with cluster who is struggling there are several factors that might make us consider ketamine IV rather than outpatient psilocybin treatment.

These include
Disability/unable to work.

Unstable mood - one of patients stopped his antidepressants abruptly to try psilocybin which didn't go well. Ketamine proved more effective.

Other serious pain disorders (ketamine tends to help)

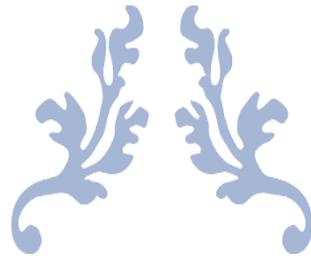
Unable to travel or obtain psilocybin

Another open question is if ketamine nasal spray is the best option after the hospital. In some cases, ketamine helps to get our patients out of the danger zone/cycle that they are in, and previously effective treatments start to work again.

A big thank you for those that helped pull this section together. I greatly appreciate your input.

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BOB'S POCKET GUIDE TO CLUSTER HEADACHES

Bob's Opinions, Facts & Observations

Volume Two - Psychedelics & Alternative Treatments

Bob Wold



JUNE 10, 2025 UPDATED VERSION
CLUSTERBUSTERS, INC

Psychedelic and other Alternative Treatments

Different psychedelic compounds have been used for hundreds of years to treat a long list of ailments including various headache types. There is evidence that psychedelics were used to treat headaches as long as 3000 years ago. In all those years, there has never been a recorded case of any overdose deaths due strictly to psilocybin or LSD.

There was a lot of research going on using psychedelics in the 50's, 60's and early 70's using psychedelics to treat everything from mental illness to curing addictions. There was plenty of safety research undertaken including its safe use in pediatric cases.

The renaissance in cluster headache treatment with psychedelics began in 1998 with discussion and anecdotal data collection centered in the website message boards of clusterheadaches.com. Those of us interested in pursuing these treatments and advancing research formed Clusterbusters to move the research from the message boards to the clinical research labs.

We first moved the discussions on the public message board to one that was invitation only in a private Yahoo board. An interested group came together over time that discussed why and how these treatments could be helping people with cluster headaches specifically. Collecting previous research, answering all the questions we had and bringing about conversations on all the new questions we had that did not have answers yet. Finding out the questions and determining the answers. Self experimentation ensued and data collected. Pulling together what came to be known as Citizen Science. All of this work and data collection eventually led to the Clusterbusters website.

The current state of this research, citizen and scientific research and available treatments is found in this handbook.

The following information will hopefully answer many questions that you may have.

The following is Important information that you'll need to understand and be prepared for should you decide to try these treatments.

One of the most important sections you'll need to read is what is found at the end of this document where I discuss treatment blockers. **Addendum 1 You will read a lot of passages throughout this document that discuss and suggest the need to stop medications we call blockers. Don't let these suggestions scare you away from trying psychedelics.**

The section on potential blockers is very important and should be considered. The list of possible blockers is a list that consists of many items that are scientifically understood (sharing neuro-receptors) and will almost certainly have an effect on how successful you'll be in breaking a cycle. Others are listed because of the data we've collected talking to people while trying

psychedelics that shows that some things block the effectiveness more so than science may suggest. Some things seem to stay with us longer than science may be able to explain. But, as quoted so often in these handbook sections, ***everyone is different.***

These sorts of changes that occur are called epigenetics. Psychedelics can change the way our genes express themselves. Just like with people, some genes can express themselves in a terrible manner. (Like that guy that stole your parking spot at Home Depot that you'd been waiting for. What? He didn't see me waiting here?)

Some things take longer to not just leave your system but to also allow your system to get back to your individual baseline metabolism. Chemicals can make changes that last longer than it's actually in your system. Ironically, this is the same thing that happens with using psychedelics. Effects can last long after the psychedelic has left the building.

When we talk about "blockers" we know that each one is different in how they block or don't block and for how long they can block. Multiply each different molecule by the differences between each patient.

If you have to stay on some of these blockers when you start a psychedelic treatment, you should still be able to tell if this new treatment can eventually provide complete relief. Something so commonly used by clusterheads as verapamil can be a blocker. Other people have been able to break a cycle while still on verapamil, as an example. If dropping your dose of verapamil or stopping it completely makes your head explode, don't stop it. Start trying psychedelics while on your dose of verapamil. If the psychedelics aren't completely ending your cycle, they most likely are making things so much better that you can safely titrate off your verapamil and it may just take a few extra doses before you get complete relief.

Each individual medication on the blockers list has it's own story. It's own problems and it's own work arounds.

Imitrex as an example will almost certainly block the effectiveness of psychedelics BUT,,,, Adding psychedelics to your treatment plan can help you get off the Imitrex so that you can eventually allow the psychedelic to break the cycle. It may just take a few extra doses. Just the first time. Maybe next cycle you can use the psychedelics early enough that you won't need to refill your prescription for Imitrex.

Maybe next time you can replace your DMT vape pen instead of refilling your Imitrex prescription. Maybe next time, you can completely skip your next cycle by taking a maintenance dose before your next scheduled Spring or Fall cycle.

When we talk about all the blocking agents, it is very real information to get to the best outcome as quickly as possible. It's certainly best to stop all blockers if you can for several reasons. Some of those reasons are also discussed in the section about the reasoning behind the 5 day waiting period.

I know that you want to end the madness TODAY. I want to end the madness for you, TODAY. But you've likely given other treatments decades to work by adding other chemicals to your cluster cocktail or giving the next new thing a month to see if it'll help and then more months slowly increasing the dose until you get results,,,,,,or not.

Please give these treatments 5 days or 10 days.

The main blockers are the Triptans (Imitrex et al.), the Steroids (Prednisone) and the ergotamine's. There are others that have issues and you may be on more than one blocker that complicates the treatment results. BUT, there are work-arounds for everything. Note the word **work**. It takes some work. But, (there's that word again) you are not in this alone and we can/will work with you.

Consider everything that isn't natural that you are putting into your body is a blocker in some way. The only reliable treatment that the medical community offers us that isn't a blocker in some way is,,,,,oxygen. Psychedelics works on a deeper level than most conventional medications. The medications we are provided treat the symptoms of cluster headache and headache disorders in general. It works best when treating YOU and your individual brain and body. Everything else changes your natural bodily functions. They tell you that they change your bodily functions. They open up new pathways or shut down old (natural) pathways. A banana is pretty much all chemicals. Your body processes that banana in a way that we've evolved into a standard process. So, all that to say, psychedelics work best when allowed to work on your own baseline human processing and repair it where it needs repair. Maybe opening up new neural pathways to replace the defective pathways. It works best when not also competing with other chemicals that are also changing the way your body is producing cluster headaches. It's like trying to teach a child to read by giving them a book that is written in a different language than they speak. Psychedelics speak "human."

Clusterbusters, as an organization and as a community, has been collecting data and more importantly personal stories since 1998. We have walked thousands of people through the process and recent worldwide survey research proves that many people are having very good results. Thousands of people worldwide are continuing to use these treatments and in many cases have replaced all other available drugs and treatments that are commonly offered by each countries approved medical treatments and medications. In most cases, there aren't issues with insurance policies covering the treatments as they are very cheap if undertaken by the patient themselves.

That said, what we have found is confirmation that each person is different and need to find what works for them. If we look at 500 cluster patients, there are 500 different paths to relief.

These is no difference between individuals using psychedelics than those with all the treatments and medications that people find with conventional medications. It's common knowledge that some people find relief with 120mg of Verapamil. Others don't find any relief until they raise their verapamil dose up to 1200mg. For many, it doesn't work at all. Some people find that it takes ten times the usual dosage that people use verapamil for when treating the disorders that verapamil was designed and approved for as a treatment dose. There are reasons that you can get verapamil in pills that have 120mg in a pill. Some people need to take one pill a day. Other's need the equivalence of 10 pills per day.

This is the same situation with psychedelics such as psilocybin and LSD. We always suggest starting off dosing with a low dose of approximately 1/2 a gram of dried psilocybin mushrooms. Depending on the effect that this dose produces, this amount may be enough for that individual and others may need to move upward in the dose until they get the best response. Similar to slowly increasing the dose of verapamil.

It has been proven over the years that the best dose is the lowest dose that is found to work for that particular person. Higher doses do not work better or quicker and is sometimes detrimental. Too high of a dose can seem to shake things up too much and will take longer to settle back into the newly repaired pain free pathways.

These treatments seem to repair the damaged or misfiring neurological pathways. It's thought that psychedelics can create new pathways that allow the pain free connections to be made rather than your broken connections that send the signals that trigger a cluster attack.

There are many things happening that are causing the cluster attacks and cluster cycles and many of these causes are still to be determined. There are also many differences from patient to patient that effect how long it may take to break a cycle or abort and attack. Part of the process seems to be allowing each neurological system to repair itself. Finding new pathways. Repairing others. There is a lot of inflammation involved in transmitting the pain signals and that keeps pressure on the nerves that then seem to be enflamed and ready to snap.

Recent research has shown psychedelics to be one of the most powerful anti-inflammatory medicines known to science. There is also something going on with everyone that I like to explain this way: The longer and more intense cycles that we find ourselves in, seems to wear a deeper pathway that needs to be repaired. It's like a river rushing downhill and wearing the river pathway deeper and deeper with each attack. Some of us have had that river flowing for decades without end or without breaks. These breaks can stop the flow, like a dam, but those breaks provided by our individual cluster headache disorder or by conventional medications, do not help fill in the deep damage dug deeply into our own pathways. When our system decides to enter a new cluster cycle, it's most easily followed by our brains to fall right back into the still deep river bed. It's just an opinion but it seems to me that psychedelics are able to allow these pathways to heal and fill the riverbed so that it's not as deep as it had been. There seems to be some repairs going on. Again, just an opinion formed by me over the last 25 years. There have not been any mice in a clinical study proving this but only because no one has stepped forward to test the theory by looking at a mouse's brain under a microscope looking specifically for this type of damage or repair.

More on how everyone is different. It makes a difference if you've been on Imitrex injections for a month or if you've been on them for 30 years and thousands of injections. Have you been using the usual 6 mg doses or have you been taking apart your auto-injectors and using just 2mg per injection? (Many people have found that it only takes 2mg to abort an attack. Increasing the number of attacks you can treat with your "too small" numbers of injections you are allowed each month)

Have you been on a dozen or more medications for months or years? Which medications are you on or have you been on for decades? Sometimes people can break a cycle with psychedelics if you are currently on some medications such as verapamil and some can not. Does this difference happen because of how long you've been on them or is it based upon the dose that you've been on? 80mg a day or 1200 mg a day? All of these chemicals we put into our bodies can have longer term effects on our natural biological chemical makeup, then just the amount of time they are active in our bodies. Some medications can actually change the way our bodies produce other chemicals naturally, or even completely shut down the natural ways our bodies react to heal ourselves and our natural ways of living through biological processes.

Many of us can attest to the fact that using some of the medications that we use for a long time will make for long term changes in how our brain works. When some medications seemed to work well for a while until our brains (or the *Beast*) figures out a new pathway to send the message to once again activate the cluster attack. Similar to the expressway roundabouts detouring us around a big city to avoid the heavy traffic. A new way to get to the destination. As a city expands, the roads get congested and traffic jams will eventually block traffic. We figure out and build a new road around the traffic jams.

An easy explanation of this is something that many cluster patients run into with some of the medications we are prescribed. Let's take prednisone as an example. I'm about to share some science. Grab a cup of coffee.

The adrenal glands, specifically, the adrenal cortex, are the organs that reduce or stop producing their natural steroid hormone, cortisol, when someone takes prednisone for a long time. Prednisone is a synthetic corticosteroid, very similar to cortisol. When you take it over a long period (especially at high doses), your body sees there's already plenty of steroid around, so the brain reduces its signal to the adrenal glands to make cortisol. That signal is a hormone called ACTH (Adrenocorticotropic Hormone), which comes from the pituitary gland in the brain.

If you suddenly stop taking prednisone after long-term use, your body might not be able to make **enough natural cortisol** right away, because the adrenal glands have gone "asleep" from disuse. This can lead to a serious and **potentially life-threatening** condition called **adrenal insufficiency**.

An **ACTH stimulation test** (often done using a synthetic version called **cosyntropin**) is used to check how well your adrenal glands respond to ACTH.

Here's why it's done:

1. To **test adrenal function** after long-term steroid use. (80mg tapered down over time is long term use.)
2. To see **if your adrenal glands have "woken up"** and can make cortisol on their own again.
3. To help decide **whether it's safe to stop prednisone** or reduce the dose.

During the test, they give you an ACTH shot and then check your cortisol levels at specific time intervals (like 30 and 60 minutes later). If your cortisol rises properly, your adrenal glands are functioning. If not, they're still suppressed.

Unfortunately I have spoken with many clusterheads over the years that had been on long term use of prednisone and had a terrible time after getting off of it, and had never been directed by

their doctors to have this ACTH shot and testing. If you've had this happen to you in the past, you should confront your doctor if it's the same doctor that last prescribed your prednisone about this or if it's a new doctor, make your experience known if they want to prescribe prednisone for you.

There will be additional documents provided with this handbook that describes additional information that explains why we are all different. Why we all need to find the treatment plan that best fits you as an individual and **what this process entails for you.**

Knowledge on Currently Available Treatments (some basics)

The process is also more fully described further on in this document.

Psychedelic Treatments - Cycle Busters

The three main psychedelic treatments are unique in their mode of action. They are often not an abortive or preventive in any of the usual sense. They are not used to abort an attack like the triptans and they are not taken every day like normal preventives. They can sometimes prevent a cycle from starting if taken early enough. They can abort an entire cycle and not just an attack. Yes they can abort an attack or low doses can end a "shadow" but these treatments, known as "busting" are not used to replace your present abortive. When used, the object is to treat "the cycle" and not just an attack. That said, there are now treatments that are abortive in nature, and seem to work even better than high flow oxygen for many people.

The doses that are used for busting and now for aborting an individual attack, are much less than what is usually taken as a recreational dose. Those used for busting a cycle are taken once every 5 days on average and not daily.

Episodics have been known to completely break a cycle with just a few doses. Chronics usually take more doses and start spreading out the time between doses. Although starting off taken at 5 day intervals, you do not take them every 5 days forever. The object is to use as few doses as possible, at the lowest dose that works, and work to extend the time between doses until the cycle has broken.

Most of these treatments are all illegal or restricted in some way, depending on where you live. Some things can be easily and legally ordered online. Psilocybin mushrooms have recently been decriminalized in many U.S. cities. All these cities have passed ordinances that prohibit law enforcement from spending any time or resources on the possession of psilocybin mushrooms. Many more cities across the country have similar laws in the process of being passed.

The supplemental documents should be read completely and have information that applies to using all the different psychedelic treatments. The most important pages to read are those that explain the warnings about additional contraindicated conditions you may have and medications you may be taking.

This important information is found in the document ***Busting Clusters***, a PDF

Contrary to what you may have heard or are worried about, there is absolutely nothing illegal or troublesome about this document or the information contained within it. As a matter of fact, this 68 page document is copyrighted in the United States and you can find a copy of it to read in the Library of Congress if you ever visit there. Speech is still protected and we've been sharing this information for 28+ years without any issues.

A. Psilocybin

The first and most often used psychedelic treatment is with psilocybin which is the hallucinogenic substance found in "magic mushrooms".

These have been used successfully by many people (thousands) for many years.

Most people grow their own which is fairly easy and can be done very discreetly. There are many videos online that will teach you the techniques. You can order the spores (seeds) online and the rest of the supplies can be purchased at garden shops or places like Home Depot. There are currently 3 states that do not allow people to purchase spores and a 4th state is working on making it illegal to order spores. There are some suppliers though that will send them to you through the mail. Some will not. Maybe you have an uncle that lives in a nearby state. You know the one. Weird Uncle AL that shows up at family reunions.

The type of mushroom and their spores, that are used, are called *Psilocybe Cubensis*. There are many varieties but they are all very similar in the amounts of psilocybin they will contain.

Consider the possibility of investing \$100.00 and you can be set up to grow your own medication for the rest of your life. Your pharmacist will be sending you Birthday cards asking where you've been all this time.

When discussing the dosing of psilocybin, amounts are always discussed as the dry weight of the mushrooms themselves and not in terms of the mg's of psilocybin found in the mushrooms. When discussing taking say, 1 gram for a dose, this is the weight of the dried mushroom. Not the weight of having 1 gram of psilocybin. Please be cautious when thinking of purchasing some of the psilocybin products that are becoming available in certain areas. They may not be accurate if talking about the amount of psilocybin found in a chocolate bar. Some don't try to explain accurate amounts at all and may say something like; "Eat one chocolate square to brighten your day. Take two squares to hug a tree"

As I've discussed about everyone being different, you can multiply that by the different amounts that can be found in some of these products.

This is one reason why it can be best to grow your own supply so that you know exactly what you have and how big of a dose you will actually be taking every time. The right dose for you and not the right dose to hug a tree. It's good to hug a tree anyway, without the help of psilocybin.

A few trusted sources.

Ralphsters Spores has been helping people with clusters for many years. You can order spores from their site at:

<http://www.ralphstersspores.com>

Premium Spores is another source. Their privacy and security is excellent. They do not retain any records or credit card info. They also take visa prepaid cards. Here is their link:

<http://premiumspores.com/>

Another one for supplies is Midwest Grow Kits. Their system is automated and it comes with a detailed how to guide. Another plus is they will ship to FedEx office locations for pickup. Here is their link: They have kits that you can order to get everything needed to grow mushrooms, other than the spores themselves. Also a lot of equipment that more experienced growers might be interested in.

<http://www.midwestgrowkits.com/>

You cannot get the spores and all the growing supplies and instructions all in one place, sorry. It is illegal. You can buy seeds and potting soil at Home Depot, but not spores and potting materials. Weird huh?

B. LSD ([lysergic acid diethylamide](#))

There is no way of procuring this other than through illegal means. Information on the treatment is on the Clusterbusters pages and instructions are very similar to those of the psilocybin treatments. You just can't grow your own.

It has been shown to have slightly better results than psilocybin and LSA. This may be due to the fact that it is a more pure chemical than using mushrooms or seeds, and that the effects can be felt for about twice as long so it is treating the cluster mechanism for twice as long as the other psychedelic treatments. Possibly providing a longer healing period.

General dosing details and tips on LSD and Psilocybin:

Following any detoxing that needs to be done prior to dosing with either LSD or Psilocybin, you should try your best to use nothing but oxygen as an abortive. If oxygen doesn't work for you, there are other ways to get through those bad days. Also, we have heard many people report that once starting their psychedelic treatment plan, that oxygen works much better than it had before dosing. Oxygen can work better for some cycles than others and it's good to not give up on it completely, for years. If it's not a difficult and expensive thing for you to have high flow oxygen around when you start these treatments, I'd suggest getting it on hand. The same medications you detoxed from should be avoided between all doses, if at all possible. You may have some bad

days between your doses and while waiting for the follow up doses. If you need something other than giving up the treatment plan and resorting back to your prescription meds, you are better off using a small amount of LSD or Psilocybin as an abortive than anything like Imitrex. This would be something in the range of a pinch of psilocybin placed under the tongue or 1/8th your dose of LSD. These small doses will have little effect on your next regular dose to break the cycle.

When you are detoxing, you may find that after a couple days, your clusters are already starting to improve. Especially if you've been using triptans for an extended period of time, you are probably causing more attacks per day than you were before you started taking triptans. This decrease in activity is actually your body going back to it's baseline number and intensity of attacks. Most people find detox not nearly as bad as they feared it would be. But yes, it can be difficult.

Prepare for a day of treatment. A dose of psilocybin will last approximately 4-6 hours. LSD will last about 12 hours. Don't plan on driving. Make sure you have everything on hand that you'll need for the day. You don't even want to have your "sitter" having to run for cigarettes. It's best to have someone you trust, plan on sitting with you throughout the process. Someone that can answer the phone and say that you're indisposed. Someone that you feel comfortable discussing some possible intimate or difficult issues. You very well may feel like you'd like to share some things you have been keeping to yourself. Its not a truth serum but you may come to some realizations that you'd like to discuss.

You will find that you don't need to hire a therapist to work on what has come to be known as Complex Post Traumatic Stress Disorder. This is caused by living day in and day out with traumatic events. Not an event that happened ten years ago that people have a difficult time navigating. We have to navigate knowing we are about to have the same traumatic event happen at the same time today and again tomorrow. We ARE complex.

What you will most likely find that this mental health issue is treated by using these low doses of psychedelics in the company of someone that cares about you and that you can trust. They are probably also having complex PTSD symptoms from watching you go through the cluster attacks. It's helpful to have someone there that you can hug, that isn't a tree. There is family healing that can take place.

A normal starting dose with mushrooms is either 1 gram or 1.5 grams of dried mushrooms. Many people start out with just 1/2 a gram. You can work your way up. You've been waiting for decades for something to work. You can wait an extra 5 days to see if this will work. I know you can. Most people grind up the mushrooms with a coffee grinder and pack it into empty gel caps. These can be purchased online and are very cheap. You can use the 0 or 00 size. The normal starting dose for LSD is between 50 and 100mcg. Again, you can start at 25mcg. This is normally between 1/2 and 1 full "tab" but you need to know your supplier. This is an issue with using LSD. Getting it from a trusted source and making sure that the product is constant in strength.

The effects that you should be trying to reach at these doses will produce the following:

- a. A slight buzz similar to a "2 beer buzz" is how most explain it.
- b. Brighter colors such as very blue, blue skies.

- c.** Slightly more separation in stereo sounds. This is why your favorite music will sound better than ever.
- d.** As to how your head feels, you are looking for a feeling of all the built-up pressure you have been feeling, draining away as if someone pulled a plug. It may feel clearer than it has in years.
- e.** This size dose is also known to put a smile on your face for 4-5 hours. If you put on a comedy video, you may not stop laughing.
- f.** As discussed earlier, you may also feel some emotions that bring tears to your eyes. You may go through many emotions. Most people comment afterwards that this is one of the best and most important aspects of the treatment. You may deal with emotions that you've been keeping inside for years. It's not a coincidence that these products are having incredible results in helping people with years of anxiety, depression and PTSD.
- g.** If you look closely, flat surfaces may have a slight movement.
- h.** The effects usually kick in between 30-45 minutes after taking the dose.
- i.** Keep some blankets around. You'll probably feel cold for an hour or so somewhere along the line.
- j.** Plan on taking off some layers of clothing at some point because you may also feel really warm at some point. The hypothalamus in your brain, where clusters seem to be originating, is your body clock (that keeps you attacks on a tight timeline) and also controls your body temperature. (among other autonomic features)
- k.** Don't go online and don't call anyone just to get something off your mind. Especially your family members 😊 You certainly don't want to be texting friends or enemies. One may become the other.
- l.** You may feel a little nauseous after an hour or so, usually only with mushrooms. If this becomes a problem, its best to make a tea with the mushrooms rather than eating the dried mushrooms. There are recipes for the tea online. Its very simple. Take the powder and make a tea bad out of a coffee filter. I know you have coffee filters around.
- m.** There is also more of what's known as body load with mushrooms (much more than with LSD) This means that you may feel more aches and pains with mushrooms. This is your body telling you where you have problem areas. Your body talking to you. If you have a bad back, it may hurt more than usual. If you had a knee replaced at some point, you'll be reminded of that.
- n.** The following day you may feel hung over. This can be helped with a couple aspirin and some coffee or energy drink.

o. More is not better. Bigger doses do not equal faster results. You may need to adjust your dose amount after the first dose. If the first dose didn't produce the types of effects discussed above you'll need to adjust. If you felt those effects and then zipped past them and felt more than these things, you should probably reduce the dose. If you never felt the clear headed feeling, you should increase the dose amount. Carefully. Increase the size by 25% each time. (**Warning Note: Doubling the dose more than doubles the effects.**)

p. This dosing works best if used once every 5 days until the cycle is broken. After a couple of doses you should try to expand the time between doses a few days each time. But don't push this if you seem to be losing ground while waiting.

q. There is a supplemental document explaining this 5 day waiting period in detail and helping to understand why we've worked out this 5 day program as the best place to start.

C. LSA (Seeds) (d-lysergic acid amide) A little different than the classically known psychedelics.

If you want to see if psychedelics might be helpful in treating your cluster headaches, this is an easy and cheap method to test out first. Although LSA is probably the least effective of the big three (LSD, Psilocybin, LSA) for breaking cycles, it will usually give you some direction and a signal that this is a worthwhile yellow brick road to travel.

Ordering LSA seeds is easy online. There are several sites that can be trusted and have been helping people with clusters get good product. You don't need to mention the seeds will be used to treat clusters and if you say you will be using them for that purpose, they can't send them to you and will cancel the order. They are, for legal purposes, "not for human consumption". They know what they will be used for. Ordering them is perfectly legal. If you've ever purchased Morning Glory seeds at a flower shop or from Amazon, you've had these seeds. You may have them growing in your garden.

One of the biggest warnings with the seeds that everyone needs to be aware of in the vascular constriction that comes along with these. Just like the warnings that come with prescription ergots, there are things everyone needs to be made aware and handle with care. Example: If you suffer from Reynaud's syndrome, you should either stay away completely or be very careful with low doses.

You should always consult with your doctor on adding any chemicals to your routine. They are the ones that will know your medical history and other issues you may have. I can't say this enough times but I do mention it repeatedly.

One place that has been around a long time is:

I Am Shamin : <http://www.iamshaman.com/>

You want to order and start off with Rivea Corymbosa seeds.

You can also use **Hawaiian Baby Woodrose** seeds but they are a little more difficult to process and also harder to adjust doses. I can tell you a lot of funny stories of people trying to crack them open with pliers and chasing these little balls, harder than chestnuts and the size of peas, around the house and under kitchen tables. They need to be cracked open and the tiny bit of pulp removed from the center. They are very powerful so nature has protected the inner pulp very well. These HBWR seeds usually only take about three seeds worth to do the trick without overdoing things. This also makes it difficult to make minor adjustments on the dose you will be trying to come up with.

I would always suggest the **Rivea Corymbosa** seeds to start.

The fewer the seeds the better in that you will then consume fewer of the ergots that are in the husks. This is why Morning Glories are the least desired method as it would take hundreds of seeds for a dose.

The HBWR though are so potent that the difference in one or two seeds can make a big difference in the hallucinogenic effects. That makes it much more difficult to adjust to the lowest effective dose.

You can search our website for more info on the use of these seeds:

People are using up to about 100 of the RC seeds for a dose for clusters. It's good to start with a small amount (10-20) just to make sure you don't have any issues with being allergic to any of the additional chemicals found in the seeds. There are some other ergots in the seeds as noted above.

Instructions for dosing with seeds:

Note: many dosing items listed above for LSD and psilocybin are also applicable to LSA Seeds.

An effective dose is most usually 60-100 RC seeds.

Crush them the best you can and soak in water for 1-2 hours. Any longer does not help and at some point will start to degrade the LSA. After about 6 hours it will actually break down the LSA content. We did research at Yale that showed that a one hour soak (in water) was all that was needed and actually produced the most LSA.

You can also soak them in clear alcohol if you like. Vodka works and will extract the LSA slightly better than H₂O. But water works fine.

Yes, vodka works, as do others, because this soup tastes awful.

You should add a dash of lemon juice to aid in the extraction. You can also dissolve a vitamin C tablet in the mix.

You should strain the solution. You don't need to ingest the husks.

You can mix the solution with something like cranberry juice or anything that has a strong taste because on its own, the solution does not taste very good. OK, awful. A nice shot of Tito's Vodka actually can help with that taste. Oh the personal research I've done for you all.

Repeat: All the same rules about dosing with mushrooms or LSD apply to using the seeds. This includes avoiding all the usual cluster meds. See the link about warnings and use of mushrooms.

This dosing works best if used once every 5 days until the cycle is broken. After a couple of doses you should try to expand the time between doses a few days each time. But don't push this if you seem to be losing ground while waiting.

If the seeds aren't giving you complete relief, it may be time to invest in growing your own mushrooms.

Psychedelic Treatments - Attack Busters (Abortive treatments)

DMT

You've probably been waiting to get to this. Thank you for reading everything else before you got here.

DMT, in general (although there is very little that is general, about DMT) is about 10x more powerful than the equal amount of LSD

Let's start the discussion with this information: A little scientific information. Also a look at where we are in our study of DMT and especially how early on in looking at it for treating cluster headache we are currently.

DMT is naturally produced in your body.

The exact amount of naturally occurring **DMT (N,N-Dimethyltryptamine)** in the human body is still not fully established due to how tiny the concentrations are and the challenges in detecting it. However, here's what's known so far according to science.

1. Detected Levels (Quantitative Data)

Studies have found trace amounts of DMT in various parts of the human body, including:

Blood: Concentrations in human blood have been reported in the range of 0.05 to 1.8 ng/mL (nanograms per milliliter), depending on the study and method used.

Urine: DMT can also be found in human urine in small amounts.

Brain (in rats and potentially humans): A 2019 study from the University of Michigan showed that DMT is produced in the pineal gland and other brain regions in rats, with concentrations in the low nanogram per gram of tissue range — levels comparable to known neurotransmitters like serotonin.

While there's still no definitive study measuring total DMT content in the entire human body, the amounts are considered to be **very small**, on the order of nanograms to low micrograms in total at any given time.

2. Where It's Produced

The human body can synthesize DMT endogenously from the amino acid tryptophan, via intermediate compounds like tryptamine and methyltransferases (such as INMT – indolethylamine-N-methyltransferase).

Detected sources include:

Lungs

Thymus

Brain (possibly including pineal gland)

Spinal cord and cerebrospinal fluid (CSF)

The human body produces DMT in trace amounts — mostly again, in the nanogram range — and it is present in blood, brain, and other tissues. These amounts are biologically significant but far below the levels needed for a psychedelic effect.

We don't know why it's there or what it's purpose is, but I have my theory, that is evolving. Will share another time so they don't lock me up in a padded room.

DMT Vape pens and cartridges. For use in treating cluster headaches.

Cartridges

These cartridges are becoming more available in many areas. Finding a reliable source, for access and for content, is a serious challenge. Cost can also be an issue but will become more affordable as more competition enters the marketplace.

The vape cartridges that contain the DMT solution are pretty universal and can be used with the different types of battery packs that are available.

There are also three different types of vape pen units. All three are available for vaping DMT.

A. There is one option available in some areas that is an all-in-one unit. It's about as long as a cigarette and about as wide around as a AA battery. All you need to do is take off the plastic cover that is on the top of the unit and covers the tip and opening. Just inhale and the built in battery automatically and immediately lights the solution upon inhalation. These can be charged but the charged pen usually lasts until all the solution is used up.



B. There are two types of separate battery packs that are used. These are also the same types of cartridges and battery packs that are used for many of the widely used vapes for smoking nicotine and replacing cigarettes, and most people are walking around and traveling with them. No one can tell the difference, including airport security. No one knows or cares what is in your vape pen. They just don't like you using it on a plane, no matter what is in it.

C. The first of these is a simple attachment that threads onto the base of the vape cartridge. It has to be charged and can be recharged if necessary. This battery is usually about 4-5 inches long and again, the diameter of an AA battery. Same diameter as the cartridge. These are usually made to turn on and off with a number of clicks (usually 5 very quick clicks) to turn on and off and then while on, can be started with one click and holding down the button while inhaling. Release the button and it shuts off but remains in standby for future one-click use, until shut off fully again with those same 5 fast clicks.

Charging device shown in picture below.



D. The second type of battery pack is a bit more complicated. With these, you can adjust the voltage that heats the solution. This option is important but not necessary for cluster headache treatment, especially while learning what the best process is for each patient. The higher the voltage, the hotter the heating element gets and then each inhalation will deliver more DMT. The hotter it can be set for will then also use up the solution quicker and possibly deliver more than you need to treat the attack.

Once the unit is turned on, by clicking the start button a set number of times (usually 5 clicks), you can then click and hold down the button while inhaling. There will also be buttons that you use to adjust the heat and voltage. We suggest using a setting between 2.0 volts and 3.4 volts. Some units can go as high as 4-5 volts and this is higher than we need and can actually burn the solution over time. The higher temps can also irritate your throat. These higher settings are used more for recreational use, delivering more DMT at one time.

With this sort of battery pack, the cartridge will need a metal adapter that is supplied with the battery pack, screwed onto the threaded end of the cartridge and then inserted into the battery pack.



Inhalations.

This is where each person needs to discover what works best for them and then knows what to do to get the quickest results for them each time.

A. Try to measure how deeply you inhale each time so you can repeat something similar each time. Measure how strongly you inhale. You don't need to breathe in as hard as possible, and should not. A measured breath in is perfectly fine. If you're a smoker, start your learning process just as you would inhale your cigarettes. If you're not a smoker, think of drinking a smoothie with a straw.

B. Try to remember how long you breathe in with the cartridge each time and try to keep them close to the same inhalation time, each time. 4-5 seconds? maybe up to 8 seconds?

If you can actually time your inhalations this is very helpful. Maybe your caregiver can keep time on their phone. Collecting data on length of time you inhale will be helpful for you as well as for research that is coming and we are collecting this sort of data so we can compare dosing. You'll find the perfect time and how deep of a breath works for you. Once inhaled, hold you breath as long as you can (10 seconds or so) but get used to keeping your inhalation time and the time holding your breath close to the same each time. You don't **need** to stop-watch to time it but try to stay pretty constant. You will need to make adjustments on this until you arrive at YOUR best and quickest abort. If you don't keep track on your timing early on, you won't be able to make adjustments. You most likely will be making adjustments that will change your time of start until the time your attack disappears. Can you end an attack in 1 minute? Probably. With adjustments can you end the attack in 45 seconds? Very possible.

C. It may take a few attempts at aborting an attack before you find the right combination.

C.1. How quickly you were able to grab your vape once an attack starts.

C.2. How bad the attack had gotten before your first inhalation.

C.3. Possibly how bad this particular cycle has been and if you are in the beginning of the cycle, the high point of the cycle, or coming out of the cycle.

These things all can play a role in many of the things we use to treat our attacks. Not just with DMT treatments.

D. Most of the cartridges will have enough solution in them to treat 40-50 attacks. But this will be determined by many things. Including the type of treatment that you settle in using, like the number of breaths that it takes, how much lung capacity you have, etc.

E, These pens are known to just treat one attack, very similarly to treating an attack with oxygen. But seem to work more quickly (within seconds many times) vs minutes with oxygen (if O2 works for you). Personally, the vape works more quickly than I can walk to my oxygen tank. It's also so much more easily carried around with you. Drop it into your pocket and it'll go everywhere you go.

Pro tip #1. If it's a bad attack that will take a couple of inhalations, and my O2 set up is close, I have used the O2 between vape inhalations. While you're catching your breath from the first inhalation, put on your O2 mask and take a couple breaths between inhalations.

F. Timing

Take in the first inhalation. Hold it in your lungs for a while. 10 or more seconds if you can but no need to push it.

Wait for 30-45 seconds to a minute to see if that's all you need. You'll know, because it will seem like an off switch was flipped.

If the attack hasn't changed, take a second inhalation. Hold it in as before. Wait another 30-45 seconds to see if you need a third inhalation.

G. DMT in this delivery system.

Each person will be different as to how much DMT they will be getting. We all end up it seems with just about the same amount in total but it may take some of us three inhalations when others will get enough in one inhalation.

When people use these for recreational purposes, they usually start with 3 inhalations. Increasing from there to get the level of effects they want. They also use higher heating ranges which will deliver more DMT. These higher rates aren't best suited for treating clusters. The higher/hotter settings will make the inhalations more harsh and may also burn the solution inside and wasting the rest of the cartridge. (Keep it under 3volts if you have an adjustable battery pack.

DMT is the most powerful psychedelic that we know of. Very powerful in very small amounts. About 10 times more powerful per mg than LSD, I believe.

But, it's not all DMT that you are inhaling. Most of the liquid solution is not DMT but the liquid transport system into your lungs. Similar to the amount of nicotine in a cigarette. All the smoke is not nicotine.

The descriptions of DMT used recreationally can be interesting but scary. One of the best things about DMT is how quickly it leaves your system. It's gone in 15 minutes on average. Sometimes 10, sometimes 20 at most. Recreational users use a lot more DMT than we need to treat a cluster attack. Recreational users talk about seeing robotic aliens and fractal light shows with closed eyes.

If you end up taking a lot more than is needed to work, and at worst and scariest you see some lights and at most extreme, you see an alien, you need to talk to them quickly with your questions, as you only have 15 minutes to ask about the universe. Honestly, reports of anything that seems scary to them at these doses, is a very rare report. Even for those of us that are more sensitive to psychedelics than others.

DMT - Alternative Source - Delivery System

This method can be sourced through underground suppliers of psychedelic compounds. There are a few sources for the vape pens that exist at some brick and mortar stores, usually under the counter, but this other source isn't something that these places carry.

You can also find DMT in pulp form that is then smoked in a glass pipe usually. It does not take much pulp in the pipe to get the results you'd like but it has it's issues. Loading the pipe with the pulp can be a hassle, especially if you're trying to do this while a cluster attack is building. It becomes more of an issue if you need to use more than 1 dose. Packing this little amount of pulp into a very tiny hole in the top of the pipe becomes more difficult with each packing process.

It is also very difficult to get a constant dose and also difficult to adjust the dose each time. If you need more, it's difficult to add a little more without adding too much. This stuff is powerful in very small amounts.

General notes on psychedelic treatments.

Yes everyone is different. I have been using mushrooms for over 25 years. I have been able to avoid many cycles but not all. If they start again, it can take a few doses again to try to break the cycle.

Usually if an episodic cycle is broken with mushrooms, it won't come back until the next cycle is due to start again. Sometimes it isn't just a clean break and you might need a few more doses as the cycle plays out but hopefully the mushrooms provide a lot more relief and cuts way down on intensity. Also, sometimes that first cycle you're trying to break is more difficult (most likely from the different medications people have been on and for how long) Future cycles can often be broken more easily than the first. Its best to "be prepared" and not wait until August of you cycles start in September, to start asking questions about growing.

An important note pertaining to high flow oxygen. If you've had difficulty getting high flow oxygen to work for you or it hasn't worked at all, it's a good idea to give it a try again as it seems that for many people, oxygen works much better after starting on psychedelic therapy.

If O2 works well for you, it is also the best abortive to use while treating your cycles with psychedelics.

When to begin dosing with psychedelics

At the first hint of an oncoming new cycle, dose. If it continues to come on, dose again.

Chronics need a more regular schedule but can usually get the doses spread out over extended times.

If you think the cycle has broken, most people can drink again without much trouble. If it's only been a few days, alcohol can still trigger an attack. If you are continuing to show improvements but still not completely broken, its best to stay away from alcohol. The more attacks you trigger, the longer it takes to heal.

Other Alternative treatments

Ketamine

Ketamine is often discussed in conversations regarding psychedelics. Ketamine is not a classic psychedelic. Ketamine can play with your mind though. It is often promoted within the psychedelic community and there are many Ketamine clinics opening up. Most of these clinics are not trained in how it is used for cluster headache or other headache disorders. Dosing and treatment plans are very different between headache disorders and the mental health disorders that these clinics are trained in providing.

I'm listing it here as an alternative treatment as it is not a treatment option that the majority of

headache specialists offer, even though it can be prescribed. It's included here because:

1. You need the right doctor. You wouldn't want a psychiatrist prescribing your heart medication.
2. You need to know what type of medication Ketamine is.
3. You need to know what it does and how to get it.

The following is a write up by one of our favorite headache specialists, that is on our Medical Advisory Board, that answers important questions.

Brian E McGeeney, MD, MPH, MBA

What is ketamine?

Ketamine was introduced into clinical practice in 1964 as an anesthetic. Ketamine was found to induce analgesia (relief of pain), amnesia and at a sufficient dose to induce loss of consciousness. The term dissociative anesthetic is used to describe ketamine and refers to subjects who appear awake but not responsive to sensory stimulation, while maintaining breathing. More modern anesthetic agents have taken over from ketamine, although it is still used in veterinary medicine. One major difference between ketamine and opioids is ketamine does not inhibit the breathing drive. Most of the opioid related deaths occur because of inhibition of the unconscious natural drive to breathe.

What evidence is there about use of ketamine for cluster headache?

There are no controlled studies and no official recommendations. Therefore we form hypotheses about usefulness or not from individual experiences. Such conclusions do not constitute proof but can be compelling. Based on my experience for years I am convinced that ketamine nasal spray (KNS) is a useful second or third-line abortive agent for individual attacks of cluster headache (CH), with a possible role in prophylaxis also. Many patients using KNS notice a reduced frequency of attacks.

Does my doctor need a special license to prescribe ketamine?

No. Most physicians have the standard DEA license which covers schedule 2-5 drugs including ketamine. Every physician can prescribe, whether they will or not another matter.

Is ketamine a controlled substance?

All medications that require a prescription are 'controlled substances'. From the Controlled Substance Act 1970, medications are grouped into 5 different Schedules reflecting their purported medical usefulness and potential for abuse. Schedule 1 substances cannot be prescribed, and Schedule 2 agents include the standard opioids such as oxycodone, morphine and stimulants like methylphenidate (Ritalin). Schedule 3 medications include ketamine and this schedule allows refills. Some countries control ketamine like opioids.

Is nasal ketamine available at street pharmacies?

Up to 2019 the answer was no. In March 2019 the U.S. Food and Drug Administration approved Spravato (esketamine) nasal spray, in conjunction with an oral antidepressant, for the treatment resistant depression in adults. Molecules of ketamine (like many molecules), exist structurally in 2 forms, mirror images of each other. Esketamine is one of these forms. Hence esketamine is ketamine. Spravato costs about \$5,000 for the first month, and \$2,500 a month thereafter and would not be covered by insurance for cluster headache (and likely difficult to get covered for its indicated use also). This is the only form of ketamine that a typical street pharmacy would have, whereas KNS from a compounding pharmacy would be \$100 a month or less.

What is a compounding pharmacy?

The main function of compounding pharmacies is to provide drugs prescribed by physicians for patients with needs that cannot be met by commercially available drugs. Medications which are available are formulated in ways which are not commercially available, such nasal sprays, suppositories etc. Strictly speaking there is no commercially available nasal ketamine, only esketamine! Not all compounding pharmacies will work with ketamine due to its Schedule 3 status, but most will.

What about IV infusion of ketamine?

In recent years there has been a great expansion of clinics offering intravenous infusions of ketamine for depression. This is much more costly than KNS and is not going to be covered by insurance for CH (and often not for depression as well). Further, the clinical experience is more profound, and can be anxiety provoking unless anti-anxiety medications are given (benzodiazepines).

What is the addiction potential?

Ketamine like many medication can result in overuse, and use despite harm. The risk of this is clearly less than opioids but remains possible with all people, especially those who are abusing other drugs.

What are the side effects?

Ketamine has a wide margin of safety. Caution is advised with all medications that can cause drowsiness. More than 20% of people who use ketamine for recreational purposes are estimated to have urinary tract symptoms but this is much less common in those who use ketamine for medical purposes only. Cases of ulcerative or interstitial cystitis (bladder inflammation) have been reported in individuals with long-term abuse of ketamine. A high KNS dose in excess of what is needed can induce distortion of time and space, hallucinations and mild dissociative effects.

Even larger doses result in a more severe dissociation commonly referred to as a 'K-hole', with intense detachment. Most people would dislike these effects.

What should a prescription for nasal ketamine for cluster headache say?

Besides stating ketamine nasal spray the prescription should state the concentration, volume and administration instructions. In my practice for a long time I used 50mg/ml (40 mls volume but can vary), with 2-3 sprays each nostril for relief of a cluster headache attack, every 8 hours as needed. Many patients who successfully use KNS need to use more sprays and I now feel that a more concentrated solution is likely better such as 75mg/ml or 100mg/ml. Most of the ketamine is broken down by the body before reaching the bloodstream. Of note each Spravato device for depression delivers 2 sprays only and the concentration is 140mg/ml.

How do I bring this up with my doctor without appearing to be a drug addict?

Well, are you? Asking your provider what they know about the use of nasal ketamine in CH is a start. You could ask them to look into it. A good option is to bring along an article which covers this use (see references).

Do I have to stop other medications?

No. Typically medication adjustments are not needed.

How do I use nasal ketamine for cluster headache?

Administer sprays to both nostrils at the onset of an attack. Both nostrils are used as the medication works by getting into the general circulation not by local action. The user needs to practice and fine tune dose to effect. Cessation of an attack requires less than the dose required to become very drowsy or go unconscious! Nevertheless, one should not drive or operate machinery after dosing, with a preponderance of caution. Many patients notice that ketamine has a prophylactic affect as well. Tolerance develops rapidly, meaning with repeated use the clinical effect lessens. For this reason I require patients to give themselves holidays from KNS, such as one day a week and one week a month.

Can I use sumatriptan, oxygen or other abortive treatments if I use ketamine nasal spray?

Yes.

How dose ketamine work, if it does work?

Ketamine in the blood rapidly finds its way into the brain where the important actions occur. We have known for a long time that ketamine causes a blockade of the glutamate N-methyl-D-aspartate (NMDA) receptor which is widely expressed in the brain. There are also other effects on different receptor families. Interestingly ketamine was first synthesized as a replacement for the related compound phencyclidine (PCP, 'angel dust'). The important sites of action in connection with CH are not known. Cluster headache is a brain disorder and there are likely multiple pharmacological opportunities to break an attack with medications that act broadly on the brain.

References

McGeeney BE. *Cluster Headache Acute Therapies. Practical Neurology May 2019. (includes ketamine nasal spray)*

The following alternatives are not illegal but they are not something that is normally prescribed to you by a doctor. They may know something about them, so you can ask about them, but it is usually the patient that brings them up. Of course, if you're seeing a doctor that follows Clusterbusters, they will likely know more about these.

A. Vitamin D-3 Regimen.

This is a vitamin and supplement regimen that has shown good results for many people.

There is quite a bit to learn and understand on this treatment and you should read all the information, not just a "Cliffs Notes" version.

It's not a difficult program to put together and will require some lab testing along the way but it can be very worth the time spent.

It is also a treatment that takes time and experimentation to determine if it will be helpful and what combination and at what doses of each component works the best for YOU.

The document itself describing all the details on the treatment can be found here;

https://vitamindwiki.com/tiki-download_wiki_attachment.php?attId=7708

This document is very detailed. It was not produced by Clusterbusters and have not thoroughly researched all the data and claims found within. I would certainly discuss this treatment plan with your doctor. Many headache specialists know of this treatment possibility. Even if they don't know about it before you bring up the subject, they will be able to discuss health issues that you'd need to be aware of and what lab testing they would want you to do should you embark down this path.

Even vitamin treatments can cause issues if not carefully added to your body. An example that many cluster patients have is that many of us use magnesium and sometimes in pretty large doses. You should be aware though that if you use magnesium for extended periods and especially at large doses, you should also be taking an equal dose of calcium. So, talk to your doctors about anything you will be putting into your body. (Including psychedelics. They are perfectly allowed by law to discuss psychedelics and it's been brought up as an ethical issue if they refuse to discuss them with you. They can't prescribe them for you but they can discuss their opinions and especially share any safety issues you should be aware of based upon your own health and possible contraindicated medications. If you need to titrate off a medication to give psychedelics the best chance of working, they should be consulted on how best to work your way off the medication in question.

Most of the items on the D-3 list had been shown to be effective in treating clusters and other headache disorders on their own. This is a combination of many of the things that cluster people had been using for years and providing some degree of improvements.

Fish oil, magnesium, B vitamins etc, all have scientific data showing efficacy to some extent. Putting them all together and adding vitamin D has been more effective than any one of them alone.

B. Kudzu Root

This crazy plant that will grow across a roadway overnight has been used to treat headaches for centuries.

Details can be found on our website. It's a supplement that can be purchased online or at your local health food shop.

The scientific research which was carried out by Clusterbusters and Dr. Andrew Sewell can be found here:

<http://onlinelibrary.wiley.com/doi/10.1111/j.1526-4610.2008.01268.x/full>

Support Therapies while using psychedelics. Some of these are also found in the other volumes such as conventional therapies.

Additional information can also be found on clusterbusters.org

1. Energy Drinks

These can be used to abort an attack if used quick enough and work pretty well with "shadows" The combination of caffeine and taurine seem to be the active ingredients that help. There are many options out there and all have varying amounts of these chemicals. Find one that works best for you with the least amount of side effects. Don't over use them, but carrying one around with you can be helpful in getting through the day. We believe that the most important active ingredient in the energy drinks that helps with clusters is the Taurine. Its best to find a drink that has the highest levels of taurine listed.

2. Ginger Tea

Again another natural herb that has long been used to treat many things over the years but has been replaced by prescription medications that oftentimes are less effective than what nature has provided.

Ginger tea can be very relaxing and not just psychologically.

You also need to remember, that just because it is natural, (as with all the same suggestions here) that does not mean there can be issues and side effects and contraindications. Be sure to read the warnings found on the CB pages.

Ginger tea is often effective in treating shadows and it's worth the try if you can use this method to eliminate the shadows, especially when they can sometimes turn into full blown cluster attacks. It can also be helpful with any nausea issues you may have with some of the psychedelic and conventional treatments you use.

OK, here comes a Bob commentary, beware.

If Ginger, which has been around for thousands of years can help you nausea rather than expensive medications, it's something worth considering. Humankind survived (a long time, (not getting into that debate) to treat their health conditions with only natural plants and herbs and things found in a forest or body of water, long before finding treatments in science labs. Ha, witches brew is often thought to contain ergotamine found in rotting bread products and those witches were actually just tripping. Maybe discovering secrets of the world and what nature provides, but certainly didn't deserve to be burned at the stake.

3. Skullcap Tea

This one is about the best one you can use if you are looking to remove some of the anxiety that you may have while taking other psychedelic treatments. It can be ordered online. If you want to try getting off of, or before getting onto, Xanax or Valium or something similarly strong and addictive, you may want to give this a try before going down that road. When using any of the psychedelic treatments, eliminating any anxiety is essential. You want to go into this with a positive attitude and removing any anxiety is the first step in doing that. It will certainly help you have a treatment dose that can lead to improving your overall mental health and attitude.

Many of the items listed here were tested in the Clusterbuster's Citizen Science Labs by many of our volunteers. This is one of those.

4. Melatonin

Melatonin is a natural hormone that your body produces. It's levels seem to drop off in cluster patients and it helps regulate sleep among other things. There have been

some studies of its efficacy for clusters and it does help a lot of people get some sleep and eliminate some of the nocturnal attacks. Its only available with a prescription in the UK but is over the counter in the US. It can leave a person a big groggy if you wake up in the middle of the night and have to head for your O2 tank so be careful. The same can happen with some people waking up in the morning. It can give similar effects as other sleeping pills. Some people have good results with as little as 3-5 mg at bedtime but others go all the way up to 20mg. Most people that report success take at least 10mg. Take it an hour before bedtime so that it's in your system when you hit that first REM sleep.

5. Magnesium

Magnesium has also gone through a few cluster headache studies and has shown some good results. It's often used in an IV cocktail to treat both clusters and migraines in ER's.

It is taken at a dose of 400mg daily and I would suggest starting it a month or so before your regularly scheduled cluster cycle is due to start for you episodics.

If you are going to stay on it for an extended period of time (if its helping) then you should also add an equal amount of calcium to your diet. Magnesium will deplete your calcium stores. This is also something you may want to consider adding to your diet if you are using verapamil as it can help with the side effect of constipation that comes with verapamil.

An Explanation for a couple "whys" you may ask

Why the 5 day wash out period and time between doses?

When you are trying to set up guidelines that work best for the majority of people, many others will fall outside those boundaries. That doesn't make the guideline any less appropriate or true.

A lot of people ate a lot of mushrooms to determine some guidelines. ;-)

For best results, generally, 5 days is best. This was based upon a LOT of data collection a long time ago and continued monitoring in a less scientific way.

Busting with psilocybin or LSD works to stop the attacks much longer than the chemicals are in your system. How and why this is possible isn't known for sure although there are plenty of theories.

Why does waiting 5 days work best? Does it work best?

Yes and there are many reasons behind it. You try to account for these things when publishing "general rules" to go by.

As someone said, if you're just starting out and you have plenty of supplies, yes there are some reasons to wait a full 5 days after stopping "triptans" but that first dose "cant hurt" if taken early. Often times I suggest using the early doses to help wean off triptans if necessary. Some people just can't break that cycle of using triptans. It can be a scary thought.

If you talk to 100 people, you'll hear 100 different stories. I've talked to thousands. It is one thing if you've been using triptans a few times a week for a couple of months. Its different if you've been using three shots a day for 3 years. It is one thing if you've been on a 5 day dose pack of prednisone. It's another if you've been on 80mg for 45 days.

A few things the 5 days gives you, "generally" speaking.

After stopping triptans, it sometimes takes 3-4 days before your clusters settle down to your original baseline of attacks. Stop the shots and your attacks often will begin to lessen. Those 6 attacks a day go back to what was happening before you started using them. Maybe 2 attacks a day that last 45 minutes instead of 90.

By waiting and allowing your neural pathways to get back to normal, and fewer hits, you will be taking on less of a challenge in stopping the attacks with psilocybin. You will be battling your clusters and not clusters made worse by the triptans.

The follow up 5 day waiting period allows you to see exactly how much progress the previous dose achieved. It takes 5 days for this. Following the dose, you may experience an increase in cluster activity for a couple of days. They will hopefully start to decrease after a few days and by day 5 you'll know where you stand.

I know people that because of this increased activity early, start dosing every 3-4 days and never realize that had they waited, they would have found that their cluster cycle could have ended. Dosing too much can continue to "shake things up" when you don't need to any more.

Waiting the 5 days gives your system more of a "shake up" and is more of a shock to the system. Maybe this plays a role in resetting the hypothalamus. Maybe not.

The triptans do block the receptors longer than they are in your system. Some meds "can" block for even longer. Part of this is how long you've been on the meds, at what doses, and each individual person. Prednisone can block for even longer than 5 days.

Why is this? Who knows for sure. Is it that triptans can deform the receptors or in some way make it harder for the psychedelic transmitters to settle into the receptors? Is there a residual effect of the triptans and ergots and steroids that set the cycle into a deeper cycle that is harder to break? Maybe.

It is true that if you dose at the beginning of a cycle before you've introduced any triptans or other chemicals to the process, psychedelics work much better at stopping the cycle in its tracks.

Another point regarding the 5 day initial detox and continuing to stay off triptans and the other blockers on the days between the doses. Regarding especially the triptans, again we know for sure that these medications cause additional attacks following administration. So, to take any shots after the first dose will cause the need for a longer waiting period before the second and any additional doses. In addition to this fact, it is my opinion, based upon some sound scientific truths, that these in-between doses of triptans are even worse than before the initial dose of psychedelics. People need to stay off the triptans once they start this procedure.

The additional hazard with in-between doses is that you will be adding more attacks in between the doses of psychedelics caused by the “come down” of the triptans. We know triptans cause more residual attacks.

Adding attacks that wouldn't be there between doses reaffirms the pain pathways for the clusters. I believe this slows the healing process needed to break the cycle.

I firmly believe that the less pain incurred during the period you are trying to break the cycle the better. The more pain involved (via attacks) keeps the pain pathways easier to pick up on the pain message trying to be sent. Therefore, if you're adding attacks as follow ups to the triptans, you're adding to the job needed to be done by the psychedelics. Using triptans during the process makes the process of breaking the cycle much more difficult, even beyond the other reasons for the 5 day waiting period.

Once you've started down the medication course, you are not only trying to stop the natural process of the cluster cycle but also how the body has changed these processes due to the introduction of synthetics like Imitrex?

We know Imitrex changes a cluster cycle and will make it last longer, be more intensive pain, and make attacks last longer. What is causing this neurological change to take place? This change certainly lasts longer than what you would think based solely upon "half-life" of the drugs. Imitrex isn't the only one that can have this effect on a cycle.

Psychedelics work for longer than they are in your system. So do some of the meds we use. Since psilocybin and sumatriptan are molecularly similar, it's reasonable to think they may affect the neurological transmitting system in similar ways for similar periods of time.

Waiting that first 5 days gives you a better chance to be working against your baseline cluster cycle and not a medicinally altered (for the worse) cluster cycle. Clear out your system, let it find itself, and then try to start healing it with psychedelics.

Bob's Busting Hacks

Busting - Best Practices

Some of this section repeats information from earlier discussions but is important to mention again in this section as it relates.

Busting refers to the process of using psychedelics as a treatment for cluster headaches. These types of treatments are also being used successfully to treat other headache disorders. The term busting is derived from the results that psychedelics have had in “busting a cycle” and ending it prematurely.

The use of these treatments began in 1998 and have since been used successfully by thousands of people worldwide.

There is a standard treatment plan that is a suggested starting point. These general guidelines can be found in the copyrighted document “Busting Clusters” which is available through the Clusterbuster Website. This standard has been refined over the years and is the most often used and successful treatment plan. This includes specific warnings that everyone should make themselves aware of as well as contraindicated medications and health issues, dosing schedules and the various choices of psychedelics.

The basic guidelines for *Busting* which work best for the vast majority of people using this method involve the following basics:

1. Detox from the list of medications that can block the actions of the psychedelics for a minimum of 5 days prior to the first dose. More on this important topic later.

Making the decision to stop all your cluster meds is usually the hardest decision you'll make after deciding to try busting. Yes the first couple of days after stopping your meds like Imitrex may be a little rougher than usual. Part of this is psychological. Knowing you have something nearby to stop the attack (Imitrex) and not using it is a difficult thing to overcome. What almost everyone that has done this over the years has found out is that after the first couple days of detoxing, your attacks start to get better on their own. Attacks may come less often and/or be less severe. What is happening is that your cycle is going back to baseline. You're returning to the days before you started using medications that can make your attacks worse and more frequent.

2. Stay off all these blockers while people go through the dosing process.
3. Leave 5 days between doses to clear all receptors so that the next dose will again attach to as many receptors as possible.
4. Wait these 5 days between doses so that you get the best results and this time period also allows enough time to determine how much progress has been made with the previous dose.
5. For chronics, after the first couple of doses, people are encouraged to try increasing the number of days between each dose. Try 5 days, 7 days, 10 days etc. Hoping to get to needing a dose once a month or longer.

Although this is the most successful scheduling and dosing, this doesn't always work for everyone and just like with every other treatment, changes can be made to find a regimen that works best for them.

For some people Verapamil works at 80mg a day. Others need up to 1200mg a day. Most people need to find a therapeutic dose through trial and error. No one is the same and no medication works the same way at the same doses for everyone.

This is also true for the psychedelic treatments. We feel that there are many factors that come into play in each instance. It seems to depend upon things such as how long they have been using different prescription medications. If someone has been using a lot of sumatriptan for many years, a workable psychedelic treatment plan is harder to find than someone that has used very little.

If you have questions about how to proceed from the beginning or if you have questions during your busting attempts, the best place to get answers and suggestions is our Clusterbusters' message board. It has people on the board that have been using these treatments for years and helping others find relief. Go to the board and post your questions in the "Busting Stories" section. You'll need to register so you can get into this private area. The link to the board is:

<https://clusterbusters.org/forums/>

Treatment Tips

There are some tips that can help these treatments work better and get to a pain free time more quickly.

1. Use only oxygen as an abortive once you've started treatments. Things like energy drinks are also well tolerated during the process without hampering the treatments. Do your best to stay away from any of your cluster prescription medications, especially the 4 major food groups: Triptans, Steroids, Ergotamines & opioids.
2. Use oxygen as quickly as possible once an attack seems to be coming. The less pain you experience the better. I feel that eliminating as much pain as possible will allow the pain pathways to heal more quickly. This "healing" starts to break the habit of the pain being triggered by the brain to immediately fall back into the same pattern. We are trying to teach the brain to use the correct pathways.
3. More is not necessarily better. It's best to try the lowest doses first and see what your lowest dose is that will produce an effect most likely to have positive results. What you are looking to feel from a dose is a light headed feeling where all the pressure in your head disappears. You should be able to feel the pain and pressure drain away. The hallucinogenic effects associated with this feeling the most would be slightly brighter colors and some enhanced stereo sound separation. The pressure free feeling should be the most apparent effect.
4. Once you've broken a cycle, be sure to have a supply on hand so that you can take a maintenance dose either a couple weeks before your scheduled next cycle or at minimum taken at the first sign of a new cycle. Do not be caught off guard and without supplies. It's much easier to avoid the next cycle with a proactive dose than to break the next cycle if you let it get a foothold again.

What to expect during and after the dose

Its not unusual to get an attack as the dose is wearing off. With mushrooms this is about 4-6 hours after dosing. LSD will take much longer and can last 12 hours. These attacks that occur after the dose wears off are not indicative of how well the treatment will eventually work for you. Get on the oxygen as quickly as possible. You may also find that oxygen works better than it ever has for you in the past.

Psychedelics do block cluster attacks from happening but it's possible that you may even experience an attack during the dose but this is rare and in almost every case is altered and much less severe and shorter lasting. Just keep the oxygen around during and after the dose.

Psychedelics are even better at blocking the neurological events occurring that build up to the attack. This is what is breaking the cycle. Stopping the build up before the attack. This is also what will appear to be a clearing of the head and pressure that goes with that. The important part of the busting process is stopping the events that build up to another attack more so than blocking an attack that has formed neurologically and about to attack.

What is the right dose amount?

What should you be looking for from the dose as far as effects that it produces? Most people start at a dose of 1g – 1.5g of dried magic mushrooms. Similarly, the starting dose of LSD is 100mcg (1 tab)

You should adjust the dose based upon the affects you feel from the dose. You are looking for the following:

- A. Brighter colors. Blue skies look very blue.
- B. Slightly wavy flat surfaces. You may not notice this unless you stare at a flat surface.
- C. Expanded stereo sounds. If you're listening to music, the drummer may sound as if he is on your left while the guitarist is on your right, even if all the speakers are in front of you.
- D. The physical affect you are looking for is a definite draining of pressure in your head. It will feel clearer than it has in years and absent of pressure.

If you've experienced these affects, stay at this dose. If you didn't reach these levels of affect, you should slightly increase the next dose. Be careful with any increases. The effects of a dose do not increase on an even scale with the amount of increase. An example is that doubling the dose amount more than doubles the affects you will feel, by a lot. Increase doses by no more than 25% each time you feel the need to increase. (More on this below in Busting Hacks)

Additional Busting Hacks - If you're having trouble breaking the cycle - Try one of these

There are some options (Busting hacks) to try that have worked for others if the basic set of guidelines doesn't work or doesn't produce complete results.

Although finding the lowest effective dose is most often effective in breaking a cycle, this isn't always what works for everyone. After trying this method, some people have tried different

adjustments and ended up being successful:

1. Escalating Dose 5 day Schedule.

This method helps keep the receptors flooded with psilocybin and allows much higher doses without increasing the hallucinogenic effects.

We can take advantage of the fact that once you take a dose, your receptors will be blocked for several days.

Due to this blocking effect, some people have been successful breaking a cycle after a 5 day constant dosing schedule. You can increase the size of the dose each day with even less hallucinogenic effect. Be a little careful with the 2nd day increase to make sure that you are getting this usual blocking effect. Remember that everyone is different.

A typical escalating dose plan would go something like this.

Day one: 1.5gram dried mushrooms

Day two: 2.5 grams

Day 3: 4 grams

Day 4: 5 grams

Day 5: 6 grams Yes, that's a LOT of mushrooms but remember, these molecules block the receptors they are looking for and there will be a lot of psilocybin floating around your system looking for a home. If one opens, it's taking the place of one that moved out and not increasing the amounts occupying receptors.

After day 5, take a break and see how you're doing with progress for breaking the cycle.

This method can also be used if your psychedelic of choice is LSD or LSA

2. Changing it up

Some people have better results with different psychedelics. If one doesn't work, try another of the options.

I would suggest getting a supply of LSA seeds to have on hand. They are very easy to obtain online and can be the first of the options you'll be able to procure. They do work well for some people and even if they don't work completely, you should be able to tell if these treatments will work for you. If you don't get full relief, move up the ladder to mushrooms or LSD.

LSD has the best results overall. If you've been using mushrooms and can't quite get over the top and break the cycle, you can try to procure LSD and try dosing with that. One of the biggest issues with LSD vs Mushrooms is that you can't grow your own LSD and if you grow your own mushrooms, you'll always know what you have, where it came from, and will be the cheapest way to go forward as years go by.

DMT is a tricky psychedelic to use as it is so powerful but the effects are short lived, as in 15 minutes. Starting out very low dose is recommended. It has always been thought that DMT might end up being the most effective in breaking cycles but very few people have either been able to access the drug or have been brave enough to go down that road. If you decide to try it, be sure to do plenty of reading on dosing and preparing for the dose. More on DMT below.

3. **Helpful during your dosing schedule:**

If you're having a difficult time getting thru the days between the doses, it's possible to occasionally take a very small dose that can get you thru the day without completely blocking the next full dose. Its not the best way to go about this treatment but its better than taking an occasional dose of sumatriptan or giving up on the process completely.

4. **Try combination dosing.**

People have been successful with combining a couple of different psychedelics after having less success with sticking to one.

One combination is psilocybin and MDMA. Adding a normal range dose of psilocybin such as 1.5g to a "normal" dose of MDMA will give a slightly more intense dose than a regular 1.5 dose of psilocybin alone.

I would only suggest that people that are experienced in using only one psychedelic give this a try. You need to be confident in what you are doing and aware of what types of experiences different doses of say psilocybin have produced for you. Everyone is different and you need to have a good handle on your own dosing effects.

5. **Adding helpful supplements**

Although we normally recommend trying to get off of anything you're taking to treat your clusters before attempting busting techniques, there are some supplements that can be help to add if you're having a tough time breaking a cycle.

There are some things that can be helpful without messing with the set of neurotransmitters that busting requires to treat. The fewer attacks that you're trying to treat, the better.

A. Add the entire D-3 regimen to your daily treatment plan.

B. See if Melatonin will help, especially with any nighttime attacks.

C. Adding 400mg of magnesium to your daily plan. If it helps, then add calcium to be safe, equal amounts. 400mg/400mg

Keep Scrolling

Addendum 1

This section is one of the most important sections you'll need to read and learn.

Info also found in the document [Busting Clusters](#)

Contains a few additional opinions and here to be included in a more detailed document

When we talk about other medications that we say can block (or in one case, enhance the effects, all of this should be considered as “generally affecting treatments.

Blocking agents and Enhancers

SURE BLOCKERS

Triptans

Perhaps the most common culprits for ClusterBuster failure are the triptans, since they unfortunately are the most popular abortive treatments for cluster attacks. Sumatriptan (Imitrex) can stop an attack quickly, and it's possible it foils the clusterbuster treatment more often than any other blocker. Other triptans are used less often, and there are fewer experiences, but for the sake of caution, these should also be avoided.

Sumatriptan (Imitrex®)

Zolmatriptan (Zomig®)

Rizatriptan (Maxalt®)

Naratriptan (Amerge®)

Frovatriptan (Frova®)

Almotriptan (Axert®)

Eletriptan (Relpax®)

Steroids

Steroids, the corticosteroids Prednisone and Prednisolone particularly, can be very effective at completely stopping cluster attacks while they are being used. They are also very effective at causing some nasty side effects, and most doctors prescribe them only for short periods in decreasing dosages.

There are many reports that prednisone will block the clusterbuster treatment.

Prednisone is one of those that can stay in the way of effective psychedelic treatments for longer than 5 days. It sometimes takes 10 days to completely clear from the receptors and let them return to normal operation. Steroids are also a problem even if you aren't ingesting them but also if you are using topical creams. Be careful.

Verapamil and other calcium channel blockers

Verapamil is a blood-pressure drug often prescribed for the long-term, preventive treatment of clusters. Most reports seem to indicate verapamil and other calcium channel blockers will interfere with the clusterbuster treatment, though a few say they successfully used tryptamines while on verapamil, and some reports seem to indicate that it impeded but didn't completely block the treatment. Verapamil is known by the brand names Isoptin, Verelan, Verelan PM, Calan, Bosoptin and Covera-HS.

So, it's best to taper off Verapamil before dosing. If you can't and decide to start the process while still on verapamil, it is possible to still break a cycle. If you seem to be getting close to breaking the cycle but just can't get over the hump and completely break it, its best to then get off the verapamil and try to break it while off verapamil completely.

Anti-convulsants

Topamax (topiramate) is another of those drugs developed for some other disease that clusterheads have found useful. Many find its side effects objectionable. There are indications it will block the effectiveness of tryptamines, as will other anti-seizure medications such as Depakote and Tegretol.

Opiates

Opiates usually have little to no effect on clusters for most, but a few say the stuff works for them, and it is too-often prescribed by doctors in desperation or under the faulty assumption that such powerful pain killers must automatically work for painful "headaches." There are many tales of emergency room doctors who are surprised and aghast when a shot of morphine has no effect on a cluster attack.

Other drawbacks

– the infamous addiction potential, while sometimes overstated, is real. It results in such medications becoming a target for theft. In any case the opiate and opioid pain killers seem to interfere with the cluster treatment. There are many in use; here is an incomplete list:

- Opium
- Morphine
- Heroin
- Codeine
- Demerol (pethidine)
- Percoset (oxycodone)
- Oxycodone
- Oxycontin (oxycodone)
- Hydrocodone
- Fentanyl
- Buprenorphine
- Methadone
- Tramadol
- Vicodin (hydrocodone)
- Dilaudid (hydromorphone)
- Actiq (fentanyl)
- Duragesic (fentanyl)
- Suboxone (buprenorphine)
- Ultram (tramadol)
- Ultracet (tramadol)

Ergotamines

Including but not limited to:

- Dihydroergotamine (DHE) (nasal sprays [migranal] and injections)
- Sansert (no longer available)
- Cafergot
- Ergomar

The molecules of these substances are very similar in shape to the tryptamines. This means they fill the same neuroreceptors as tryptamines, and interfere with the clusterbuster method. They can have some very serious side effects as well. They are powerful vasoconstrictors, and can cause bad circulation problems, particularly in the fingers and toes.

SSRIs

SSRIs, or selective serotonin re-uptake inhibitors, widely used to treat mood and other psychological disorders may be blockers, as they are involved with serotonin. The SSRIs include Prozac, Celexa, Lexapro, Paxil and Zoloft.

Other similar serotonin-affecting drugs include Effexor, Pristiq and Cymbalta. Drugs known as tricyclics, including Elavil and Tofranil. may also interfere with tryptamine treatment.

ENHANCERS

Lithium

People taking lithium, whether it is for preventing cluster headaches or for some other reason (it is often prescribed for people with bipolar affective disorder).

Anecdotal reports suggest that lithium can greatly potentiate the effects of LSD or mushrooms, and that it can produce very unpleasant feelings. An examination of a number of reports suggested that lithium can either increase or decrease effects.

The combination of lithium and tryptamines may even produce episodes that seem like, and that perhaps are, epileptic seizures. If people are taking lithium for treating cluster headaches and it is not working, they may want to talk with their doctor about tapering off and not taking it any more before trying mushrooms or LSD.

If people are taking lithium for bipolar affective disorder, they probably should continue taking lithium, and they should avoid taking tryptamines for cluster headaches.

MAOIs

Monoamine oxidase inhibitors (MAOIs) such as Nardil or Parnate are prescribed for depression and sometimes other conditions. They can block the action of enzymes that can break down some tryptamines, and as such may act to intensify the action of a given dose of tryptamine, especially when first taking tryptamines. However, after continued use (as perhaps after a month or more), MAOIs will tend to reduce the psychedelic effects of mushrooms and LSD. It is not known if long term use of MAOIs will interfere with tryptamine treatment of cluster headache, but it is possible.

NON-BLOCKERS

There are substances which will probably not interfere with the actions of psilocybin:

- antibiotics
- NSAIDs (non-steroidal anti-inflammatory drugs) such as Tylenol (acetaminophen), aspirin (ASA), ibuprofen, Vioxx (rofecoxib), etc.
- antacids and anti-ulcer medications
- asthma medications
- insulin
- caffeine
- caffeine/taurine energy drinks
- Tylenol
- aspirin
- B-Complex and multi vitamins
- Diovan (blood pressure)
- protonix (for acid reflux)
- Indomethacin
- meclizine and dimenhydramine (The anti-nausea agents)
- Lipitor



BOB'S POCKET GUIDE TO CLUSTER HEADACHES

**Opinions, Facts & Observations
Bob Wold**

Living Life With Cluster Headaches

Volume - Three



Before getting into some discussions on life with clusters, let's chat about a couple of the more mechanical issues we have to deal with that can interrupt our day to day lives.

There are many different options available today. Some of which you may have tried and others that are new. There is more research going on right now for cluster headaches than any time in history. Some brought to us by medical science, some still in the research stage that you can participate in, some that have been developed by what is known as "citizen science" (The cluster headache patient community itself) and some being developed by medical device manufacturers. New options, some coming out of labs, some from nature, some from medical engineers. We have always searched for hope to keep us going. I can report honestly and tell you that there is more reason for hope for a future of better treatments, easier to find qualified doctors, a more educated public (friends and family), than ever before in history. We have made more headway in the last 15 years than at any point since cluster headaches were first noted in medical journals in the 1600's.

It is these sorts of things going on in the background and should be always kept in mind when contemplating your situation.

Some miscellaneous tips & notes on conventional prescription medications.

When discussing any medications, whether they are prescription, over the counter or natural remedies, it is important to remember that old adage we've all heard before, "everyone is different."

Some people have much more severe cluster cycles and attacks than others. Just as some of our attacks are 10s and some are 2s, some people have cycles that are 2s and some have cycles that are 10s. One thing no one should ever feel obliged to do is either justify their pain levels or minimize the suffering they endure. No comparing is allowed. You have what you have and others have what THEY have. Some people will get cycles that are worse than they've ever had before and some will experience cycles that are possibly shorter than usual or not as severe attacks. Some may have good treatment plans that may not work as well for their next cycle. All in all, all we know is that we all have cluster headaches and they are never less than life changing and the fear of the next cycle is always there. We have the same levels of fear.

Some people are able to treat their cycles with low doses of medications and others need much higher doses before getting to a therapeutic level. This does not seem to have any correlation with the length or severity of their cycle. Some people can stop a cycle that is very severe with a low dose of a preventive. Others have much less severe cycles but need very high doses of anything to get any relief.

All that said, this is true, many symptoms can be different from one patient to the next, severities may differ but the totality of the cluster diagnosis is terrible and difficult to live with.

Some life issues we end up dealing with day to day.

1. Going to the dentist?

If you're going to have dental work done, and need a shot of Novocain, ask for the injection without the Epi. Epinephrine can induce a cluster.

It's also a great idea to teach your dentist a bit about clusters and that the dentistry profession misdiagnosed more than 40% of clusterheads and had dental procedures done hoping it would help your headaches/toothaches before being properly diagnosed. Teach your dentist for the next person and they can also help educate others in their profession. Toothaches do not happen every night at 3am and last just 45 minutes, EVERY NIGHT. Then go away completely until another hits at 2:00 pm for 45 minutes, and quickly goes away completely.

This can actually be true about something you can do for the community and for those yet to be diagnosed. We are out there trying to educate the entire medical and healthcare system on everything from diagnosing clusters, to helping them learn how to help us gain access to treatments. Finding medical supply houses that can provide oxygen or other medical devices. Help getting prescriptions filled and approved by our insurance companies if we are lucky enough to have insurance.

2. Getting out. Don't be afraid to travel.

If your insurance company covers O2, your supplier can most likely have O2 waiting for you at a hotel you are staying. Just call and ask for a rep that handles travel plans. They'll work out a deal with a local supplier. Bring your mask and regulator with you on your trip.

It's true that air travel can trigger an attack. I've heard it said that if you take a capsule of mushrooms prior to leaving for the airport, it can help you avoid that problem.

People have also had some luck asking the flight attendants if they can get you an oxygen tank while you're in flight. They can ask the captain for permission. They will have a tank onboard for emergencies. It's best to have a chat before taking off or shortly after take off and leveling off and have that talk before you try asking when an attack starts. They will need to talk with the pilot for permission.

If you use something other than oxygen for treating an ongoing attack, pack it in your carry on and keep it handy.

It's not easy to get past but try not to let the fear of cluster attacks make you cancel life activities. It's bad enough when attacks do ruin an outing but try not to let fear make you cancel. You'll end up cancelling a lot more activities than you would have had to.

Cluster used to be called “executive headaches” because many people working stressful jobs would be fine all week and then the clusters would hit during weekends, when the person would relax. It’s a matter of adrenaline keeping the clusters away sometimes. Going on an adventure or a graduation or birthday party just might be something to keep some of those attacks away.

3. Pain is inevitable; suffering is a state of mind and is optional.

One of our biggest complaints as cluster sufferers is all the things that they take from us. Jobs, relationships, important events etc.

Don’t let fear take away more than the clusters would have taken on their own.

If you think about the best times of your life, it’s a collection of memories. A collection of moments. You can still have those moments in between the attacks, before the attacks, and after the attacks. You need to go get them.

Consider when you’ve been asked things like, “how was your vacation?” You rarely describe a trip in totality. No one wants to look at 100 pictures on your phone. But they will look at a couple of those special moments.

You mention a long string of fantastic moments. Maybe just a few moments. That 1/2 hour fight you had while fishing and landed that fish you have mounted over your fireplace. If describing your family trip to Disney World, you mention how excited your child was to meet Mickey Mouse. The great meal you had on the Riverboat.

You can still have all of these moments, even if your day is interrupted by clusters. Hopefully you have some reliable abortive. Your family would prefer to have you with them with your oxygen tank than be stuck back home by yourself. Whatever the case, you can always pick yourself up and head back to the beach to where your family is hanging out and build more moments.

A. Marriage & Relationships

50% of marriages end in divorce. 99.9% of those do not have clusters in their lives. It’s “only” about one in every thousand marriages have clusters in their home. Life is hard..It’s hard for everyone that doesn’t have the added burden of cluster headaches.

When we in the community complain that someone has left us because they weren’t strong enough or care enough to stay because of the clusters, this diminishes the wonderful people that do stay regardless. Leaving is the normal response. Staying and supporting is the exceptional response. Your caregiver deserves the respect they’ve earned through their dedication to caring for you and not giving up.

We did some research long ago that showed that 29% of cluster relationships end due to what they felt were caused by the diagnosis of cluster headaches. I think that sometimes it's the clusters just push things in life over the edge. Relationships are rarely easy for anyone and it takes work. Clusters certainly do add a lot of stress into any relationship.

If you aren't one of those rare couples that find each other because of their common cluster headaches, then neither person knew what they were signing up for when they pledged to be there for each other for "better or worse."

One thing that is true after meeting cluster families for almost 30 years, is that when someone is diagnosed with cluster headaches, that diagnosis doesn't just cover one person, a cluster diagnosis affects the entire family. The family is diagnosed with cluster headaches. This information isn't anything new for you to be told about. You're all living it every day.

B. Jobs & Workplace

Everyone loses jobs. No one stays anywhere for 35 years anymore. It's long been suggested to change jobs every three years if you want to make the most money and rise up in any field. Everyone has trouble holding a job because everyone has personal issues. Not only are there ways of making a living, especially in today's cyber world, your goal should be to make a "life" not a living.

If you're having trouble at work with getting them to accept your health condition and they don't appreciate having to make accommodations, this is certainly a widespread issue for us and has been this way the first time someone gave someone else a job and had to pay them. It happened even if they weren't paying them and were slaves and owned by their bosses. In today's job market, many people are still treated in this way. It seems to be getting even worse. So, don't be thinking that it's all because of your clusters.

Tell them that you have a plan and stick to the plan. Keep them updated on changes ahead in treatments. Let them know that you're doing more to not only continue to be the good employee that you are but you and your team have a plan to be even better. It's best for you to have a positive attitude about the future and you should be sharing with them, the positivity of getting better over the long haul. Tell them that there will be ups and downs but you aren't going to let the downs eliminate the ups. Let them know when you find some relief with a new treatment plan. Let them know when you hear about new research coming down the road.

Your mental health and physical health will always be best if you have a positive attitude. This should also be the attitude you bring with you to work.

Yes, I know that this is easier to say than to do. Remember that I've had clusters for 45+ years. Two cycles a year except for the 5 year period where I was chronic. The ups kept me alive through the downs.

I keep a note in my wallet that a friend slipped into my wallet years ago. It's quite tattered. All it says is "It'll get better. It always does."

C. PTSD & your mental health

A big part of understanding these issues is accepting the fact that cluster headaches very often cause severe "PTSD symptoms." The fears we deal with are not something that we can easily get over. Just as we should never just expect a soldier coming home from war to "just get over it" we shouldn't expect ourselves or those we support to "just get over it." PTSD is PTSD. Reach out for help. Keep reaching out until you find that help.

Surround yourself with supportive people.

Society oftentimes teaches us to believe that it shows weakness to ask for help. It's not a weakness, it's a necessity and displays more strength than weakness.

Research going on currently looks at something like cluster headaches as producing what is actually now called Complex-PTSD.

Complex because the trauma that is causing the PTSD is actually still occurring, day after day and from one cycle to the next. It's not caused by one particular traumatic event. It's not an attack on the battle field or car accident or an event that is over. It becomes pretty complex to treat if the trauma is still occurring. This PTSD still exists in between cycles. We all have the fear about the next cycle. So, this is closer to regular PTSD as it is what we are dealing with after a cycle ends. But, it's also more complex. Most people with PTSD suffer from it because it is POST the trauma event and the fear of it happening again is real but in most cases, that traumatic event isn't going to happen again (yes I realize that for some, they too will suffer similar events unfortunately) the odds are that we will be visited by that traumatic event again, even if it's a year away. It's not something that we can try to avoid. This isn't any situation that we can refuse to allow happen again.

D. Tips to treat your clusters as well as your mental health

Build a plan. Write it out. As I talked about above, share it with the people in your life, like your boss and family. Write it out for yourself and be as committed to that plan as you are to living a good life and beating this atrocious disease. Let people know that you've got a plan to get better and stay more healthy. Did you previously like to go jogging or go to the gym? Have you stopped? Set a plan to get back into doing those things that were important to you. The plan does not have to be, "tomorrow I'm running that marathon." Maybe it's just walking around the block. Drag that O2 tank with you. They make two wheeled dollies to drag it behind you. You and your family will be happy that you are dedicated to getting back into shape. Or happy that you're working toward getting back on the water to go fishing. Reintroduce yourself to your passion. It's important to work at being as healthy as you can. It'll provide strength to get through your cycle. Most of us have vices that make it a less than healthy lifestyle. I'm told that a pack of cigarettes and two POTS of coffee every day isn't the best healthy lifestyle. I do know that whatever we do day to day needs to

be as healthy as possible and sometimes we have to be healthier than others in different ways to make up for our bad decisions.

E. Let's talk some more about your mental health

Clusterbusters has learned a lot about mental health when it comes to people (and families) that live with cluster headaches in their lives.

Once you are stricken with clusters, you'll have mental health issues whether you are chronic or episodic and in or out of cycle.

One of our biggest fears and that adds to our traumatic events is to have our caregivers and family and friends bear witness to our trauma and not being able to help in any meaningful way. To counter that belief a bit, let me just say that just being there for us, and knowing they are there for us, IS helping in a VERY meaningful way. I can say that everyone that is in our cluster community and is the one physically dealing with clusters, greatly appreciates not only their own caregiver but has complete respect and admiration to all the caregivers in our community.

We are like fans of a symphony. We may have our favorite musical instrument on stage but love the sounds made by the entire ensemble.

Clusters are known as producing self inflicted isolation. One of our first instincts is to hide our attacks as much as possible so that people close to us don't have to witness our attacks. We know it's a traumatic event for ourselves and want to keep that trauma away from people that care for us. It is traumatic knowing ourselves that there is little that we can do but we also know that they too will have those feelings of helplessness.

After speaking with literally thousands of caregivers, I can attest to the fact that no matter how you may try to prevent it, your caregivers are also going through a traumatic event even if they don't see you. What helps with that trauma is to see you recover from it and get up and enjoy the time you can spend with them.

F. Community

We are here for you. If you are tired trying to explain yourself to family or friends or your boss, reach out to someone at Clusterbusters or a friend from the community. One of us will be more than happy to have a chat with them and will *"bring the receipts"* to the discussion.

If you're not too sure this would help or that no one would want to do that for you, sign up for one of the zoom support calls and bring the subject up.



BOB'S POCKET GUIDE TO CLUSTER HEADACHES

**Opinions, Facts & Observations
Bob Wold**

Research & The Future & Hope

Volume - Four



If you think you've tried everything and there are no new options, you're wrong.

There are many different options available today. Some of which you may have tried and others that are new. There is more research going on right now for cluster headaches than any time in history. Some brought to us by medical science, some still in the research stage that you can participate in, some that have been developed by what is known as "citizen science" (The cluster headache patient community itself) and some being developed by medical device manufacturers. New options, some coming out of labs, some from nature, some from medical-chemical engineers.

Even if you aren't a fan of psychedelics for treating your clusters, you, as a cluster patient or caregiver, should be a fan of this truth. The research that we have conducted and have had published has invigorated the conventional medicinal healthcare system to start and advance more "conventional" treatments than ever before. Big Pharma has looked at new research opportunities and some have already been approved by the FDA for use. Psychedelic research has discovered new pathways that have an impact on the root cause of cluster headaches and other headache disorders. The amazing long lasting results of some psychedelics that we've studied has shown indications of the deeper process and looking into more of treating the cause of clusters and not just following and treating the symptoms of clusters. Getting us closer to a cure than just treating the effect and symptoms of clusters.

Years ago there was a very efficacious treatment for clusters that helped many people. Especially helpful for the hard to treat chronic cluster patients. It's brand name was Sansert and was known as Methysergide. This was a modified LSD molecule. Psychedelics have long been known to treat headache disorders. Methysergide was the government's attempt to block the hallucinogenic affects of psychedelics but still work for treating cluster headaches. It worked for many. It was taken off the market for unfortunate reasons. It was only being used by a small percentage of the population. A small market share. It had also been producing some bad side effects with some people. Doctors and patients though worked through that problem because it was so helpful, and found a way to avoid those side effects. This was a small pill taken once every day as a preventative. (Better than any preventative available today) It was discovered that if the patient went off the medication for one month, after every six months of daily use, these side effects disappeared. The known side effects cut into the amount of prescriptions being written. This decrease caused the already small market share to not being able to support the profit margins required for a company to continue producing and selling it. They couldn't make enough money to continue keeping us alive. (OK, so this is one of those "my opinion" moments.)

Psychedelics have gotten us a lot of air time. It seems that we are an interesting patient community and the healthcare system.

I'll chat about "side effects" a little more in a different volume.

The following is a list of options you may want to consider and keep an eye on in development, in no particular order.

Keeping up to date

Things are moving quickly so this is just today's happenings. Be sure to keep up on what's happening on our website and visit us at our next conference. Speak directly to the doctors and research teams working on finding new and better treatments.

Research & Clinical Studies

There are several studies going on or in the process of starting soon and Clusterbusters is involved in many of them.

I would suggest signing up for our patient registry so you will get all the latest news and info on upcoming clinical studies. This sign up can be found on our website at www.clusterbusters.org This where you will always find new updates on what is in the process and what is still in the thinking stages.

Patient Registry

As announced at our conference in September, we have several clinical studies in the works. Some of which will most likely be asking for study participants within the next 9 to 18 months.

These studies involve do or will involve, genetics, psilocybin, DMT, and a couple others including one involving the psychological burden of cluster headaches. People are studying not only the cluster headache disorder but also the cluster headache patient. We are a complicated and unique community. We always will keep everyone up to date on the other studies that we are working closely with the device, or research labs.

Anyone wishing to participate in these studies should be registered in our Patient Registry. In some of the studies, all participants will be invited strictly from those that are on our registry.

Clusterbusters and our community funds and operates many of our own studies. Studies that others can then also take up and build upon. Some of these clinical trials will have study sites outside the United States as well as within the US.

This is an international registry and we are looking for people from every country to sign up. A couple of these studies in particular will be looking specifically for people living in the UK, Germany and Canada. Please share this information with anyone you may know residing in these countries.

A. Psilocybin Study

We have an ongoing psilocybin study at Yale University along with the VA and are currently not yet accepting patients for the next round yet. We will alert everyone as soon as it opens up for registration. If you have wanted to try psilocybin to treat your clusters and for any reason haven't been able to, such as not being able to procure the materials, or have issues because it is still

illegal, this is an FDA approved clinical study. You will just need to be able to get yourself to Connecticut. It's also possible that this next round may have added new clinical sites.

There are also a couple other psilocybin and related molecules in various development stages working towards different phases of clinical study.

B. BOL-148: Research, Development

This substance is an analog of LSD and has been around many years. The early study done by Clusterbusters showed extremely impressive results. Further study and development has long been delayed due to the usual drug development issues and not because of its efficacy. Keep your eye on it as we still believe it will be further studied and eventually developed for use. The process for getting FDA approval for cluster patient clinical trials has begun and we will be keeping everyone up to date.

As of this date (06/01/25) this study is half way through the phase one status which is an FDA required trial where healthy patients (without clusters) are given the BOL-148 and safety data is collected and then presented for approval to undertake phase two where cluster patients will receive BOL-148 in a randomly controlled trial.

This study is currently waiting for additional funding to propel this expensive process forward. Additional information regarding this research can be found on our website.

C. "Cluster Headache Medication and Psychedelic Use Survey"

This study Survey has been completed and will be the largest survey of this type for cluster headaches and the use of psychedelics as a treatment that has ever been undertaken. The data is in and currently being evaluated and written up for publication We expect at least 4 peer reviewed research papers to be published. The data collected is already helping to inform additional research studies that are in various points of completion. Some soon to be in phase two studies.

D. DMT Study

Yes we are in the early stages of conducting studies using DMT as an acute treatment. One that seems to have an efficacy and speed that works faster than even high flow oxygen. We are currently working on a study that has already been approved by the IRB (Independent Review Board) on the very prestigious university the study will take place. Keep an eye out for this promising development.

E. Various Studies in process and yet to have been officially announced.

We are actively working with numerous companies in early stage development of new treatments. Everything from new Neuromodulation devices to psychedelic based, to new molecules being studied to treat cluster headaches specifically by pharma companies. At least two of these will be announced by the end of 2025.

Keep Scrolling ;-)



BOB'S POCKET GUIDE TO CLUSTER HEADACHES

Opinions, Facts & Observations – Issues confronting cluster patients when trying to get from access to proper diagnosis to access to “available” proper treatments.

Gatekeepers

By Bob Wold

Volume - Five



Prelude:

It has been a 25 year journey trying to get better recognition and better treatment for cluster headache patients. There has never been a day that we haven't found new gatekeepers standing in the way of everything from education to the development of new treatments and finally fighting for access to these treatments. What good is coming up with a good idea and spending years and millions of dollars developing help for our community if in the end, they can't get access to it?

The current state of the evolution of our society and the existing healthcare systems (different in every country) seems to keep us all marooned on an island and having no one that will allow us to book passage to the mainland.

We have found that there are literally thousands of people that have the power to put their stamp of approval for our application for a passport needed to book our passage to relief.

In this volume I will list out some of these gatekeepers and what it takes to get us past them to find relief. We find ourselves standing in more lines to nowhere than we would find ourselves having to wait in line at the DMV, every day.

Section 1. Getting a proper diagnosis.

Yes, this is usually the first hurdle we must get past. Getting a proper diagnosis. The main issue here is the education needed that simply does not exist within the majority of our healthcare systems. It's not difficult getting a proper diagnosis IF you happen to get lucky enough to find a physician that has been educated in headache medicine and learned the differences in the nearly 200 different headache classifications. Only one of those will teach about how to recognize and diagnose cluster headache. Most of us can diagnose another cluster sufferer after asking only a handful of questions. Five minutes asking a few questions and looking into the eyes of a cluster patient.

I was misdiagnosed for 4 years by many professionals. Eight cycles that all had lasted 3 months. Two years worth of days in cycle.

It took a headache specialist 10 minutes to utter the words for the first time hearing them, that I had something called cluster headaches. 10 minutes after 4 long years suffering from the worst pain known to mankind. 4 years on my hands and knees begging for help.

Here's a few of the gatekeepers that I ran into while working my way to that diagnosis. I'm sharing this just as examples of what we all seem to go through unless we are very lucky.

My family doc, who I had for 40+ years, thought that I was getting some sinus infections (or something sinus related). After putting me on several medications and making them stronger after each visit and reporting no relief, the cycle would eventually end on its own and we would both think that we had finally found the cure. We didn't.

When the clusters returned, we worked with what we thought was the key the last time I went into cycle and work from there. Three months later we thought that we had again finally found the cure.

The next cycle I started exploring for someone else, another “expert” and would go through the same ritual. Who’d I see? A dentist. Teeth getting root canals and then extraction. A chiropractor. That didn’t work and we thought it was a brain tumor. Saw someone to get a C-scan to find the tumor and it wasn’t there. Good news? Not really. Still didn’t have any answers. Then on to a pain specialist. Went on heavy opiates. That was useless. Went to a neurologist. Finally an expert. I was then getting medications designed for treating epilepsy.

There were other’s along the way.

Finally I went into a headache clinic and was told ten minutes into the appointment that I had an obvious case of cluster headaches.

Here was the case to be made that a long list of doctors and other professional healthcare providers needed some education.

There are over 1,200,000 licenses physicians, dentists and chiropractors, not to mention all the other specialties like acupuncturists, in the US alone. There are less than 1000 headache specialists in the US in total. What are your odds of finding one of them?

In 2018 there were 15,000 Neurologists in the US. Most of them have only heard about cluster headaches in passing. It’s believed that they only get about 1-2 hours of education regarding headache disorders and remember, there are close to 200 different headache disorders. As a result, almost every woman that sees a neurologist with cluster headaches is first diagnosed with migraine. Mistreated sometimes for decades as having migraine.

Issues: A. Finding the right doctor

Clusterbusters is in the process of building a list of qualified doctors that know how to diagnose and treat people with cluster headaches. It’s not easy. If you ask them, they all know. We know that isn’t the case at all.

Look for someone that has been referred by another cluster patient and look for, to start, a headache specialist.

B. Understanding the basics of what lies ahead

It’s not just educating the professionals. It’s also educating the patients. You need to know what symptoms to convey to your doctor that are important.

There are some basic symptoms that all need to be explained. Missing one or two can complicate the diagnosis. If you have these, tell them. Don’t let them cut you off and make assumptions before getting them to write them all down in your medical records. Everything that goes in, or doesn’t go in, will have major implications for decades.

A few of the major points to be made, for everyone of you see.

1. Even though your attacks come and go all day and all night, you should not explain that your attacks last ALL DAY. You need to make it very clear that even if they last all day, they come and go. It's not one long headache. You aren't in that pain all day. There are definite breaks between attacks.

Know one ever has a bad toothache that comes on every day at 2:00 pm or 4:00 am every day and only lasts one hour. Then goes away completely. You need to make those breaks known to whomever you are talking with.

By revealing these breaks, you aren't minimalizing your pain. By telling them that it "only" hurts three hours a day does not minimize your pain and suffering. But it will differentiate you from getting diagnosed with everything from a toothache to a migraine to tension headaches.

2. Be sure to mention the autonomic features if you have these.. This is the reddening and watering of one eye on the side of the pain. The droopy eye on that side. The running of your nose, on that same side.

3. If you've been through a cycle or more and now you're heading back into another, make that known and detail when these past cycles took place and for how long. Once again tying your clusters to the hypothalamus in your brain. Mention anything that relates to the timing during the day/night and timing of seasons.

4. Tell them that describing your pain level is difficult. There are no words in the English language that can describe the pain, both physical and mental pain.

They may show you a chart that shows 5 smiley faces and ask you which one fits your pain level. Yes, you can get mad, or laugh at them. Tell them that society does not allow for the faces you'd make an emoji to describe your pain to be published on public forums.

5. You need to be honest about your pain. You do not need to be asking yourself if you are really in this much pain or are you just a whiner and weak. The fact that you drop to your knees and cry does not make you weak. It proves your strength in being able to survive such pain. That is the attitude you need to walk in for your appointment and express to them.

6. This thought of weakness creeps up upon all of us starting with the first attack and feeling the impact of your pain upon your family. Does your family feel like you are letting them down by not being strong? Are we letting them down?

I can honestly say that after speaking with thousands of caregivers, one of their biggest regrets is not being able to fully explain how impressed they are with your strength and are certainly not seeing weakness. They aren't hiding the guns and knives in the house because they think that you're weak. They do it because they love you and care about you.

Last note on this subject about the lack of education we need to deal with and fight against.

I recently went through chemo and radiation and immunotherapy for cancer. After I started treatments, and on a monthly visit with my oncologist, he asked me how I was doing. Well, I said, I'm fine except that the chemo was triggering my cluster headaches and it looked like I'd be in cycle until chemo ended. I wasn't complaining, just sharing. I wasn't angry, just answering his question.

His response, was this. He was saddened and offended that he was trying to save my life and I was complaining about "headaches."

I didn't apologize but I just moved on with the conversation. I wasn't up for trying to educate this doctor. I didn't mention how offended or disrespected I was feeling.

Section 2. Getting proper treatment plans

Issues

A. Oxygen

This is the first thing that your doctor should be prescribing for you. High Flow oxygen with tanks, high flow regulators and the proper mask. Even some headache specialists resist prescribing oxygen properly, if at all. This is something you need to demand and the doctor's office staff needs to be prepared to fight all the gatekeepers you'll find along the way in getting oxygen tanks and the proper set up delivered to your home.

We have a deep collection of information about oxygen and getting past the gatekeepers on our website.

B. Don't be your own gatekeeper. See volume 3 Build a plan

Section 3. Finding support

You need to reach out to other sufferers to find people that understand without having to explain yourself. The best way to find your community and how important they can be in your life is to actually show up at a Clusterbuster's Patient Conference that happens every year. It's incredibly important to both you and your caregivers. They are every bit as invested in your care as you are and come up against the same feelings of helplessness that you have. They also need community support that looks at all of this from a different perspective. You aren't the only one that feels misunderstood.

Section 4. A partial listing of gatekeepers you'll find along the way. I've learned that an entire list of them along with a description of how and why they stand in the way, would take a very long book to be written.

A. Diagnostics

All those that misdiagnose you and keep you from getting a proper diagnosis and treatment plan. The millions of professionals standing in the way because of lack of education or empathy.

B. Insurance

Many different individuals and company departments that keep you from getting insurance to pay for the most important treatments. The more effective they are, the more expensive they are, if having to go through insurance. There are different agencies that also play a roll in what gets approved and what access we may get, and at what cost. There are agencies that look at a new drug and decide if the price that the pharma company wants to charge, is fair. If they decide it's not worth it, the drug may still get approval but it'll probably never be approved to be covered by insurance. There are many gatekeepers along this road to access.

C. Legislators

We make a trip to Washington DC every year to fight against all the laws and regulations that stand in the way of getting care. This is not just keeping us from new psychedelic options but also many options that could be available through your pharmacy or medical device manufacturers.

D. Medical supply companies

All those that make it difficult or impossible to get home oxygen. They all like to only prescribe home O2 concentrators. They can charge monthly and only have to delivery once. Many will not provide specifically to cluster patients. This in one reason that sometimes our best friends are providing us with Welder's oxygen.

E. Regulatory government agencies.

There are many agencies that stand in our way. From Medicare and Medicaid to the FDA, the DEA, the many Governmental agencies that regulate other industries from Insurance companies to pharma companies. Different agencies regulating our healthcare availability for the many different communities. Dozens if not hundreds of gatekeepers depending on whether you live on a Native American reservation or if you're poor or if you live in one state or another. I could make a long list of all the different gatekeepers in different government agencies with federal agencies multiplied

by state and local agencies. Within each agency there are dozens of desks that reform and improvements in care land on throughout any change.

There was once a lawsuit against the DEA about signing off on an approval for a new drug that showed great promise. The DEA was only charged with the requirement to sign off on the application so that they were aware of this new approval. By charged with, I mean that was their only responsibility in the process, to sign off and move it along.

They were then charged with having to sign off based upon the laws and regulations. They lost and were instructed to do so by a federal court. The DEA representative told the court that, ok, yes, we will sign off on it, BUT, there is nothing in the regulation about how long we have to sign off on the approval and that if he wants to, (and he wants to) it will sit on his desk for 8 years or as long as

he wants. This was almost 20 years ago and the approval was never signed. It's still sitting on a desk on Washington DC.

F. Universities

Found at all levels of higher education there is never enough education into any of the steps involved in providing proper care to headache patients. Never enough hours spent on educating any of the various professionals we will find standing in our way. It's always hit and miss. Many times it may end up being a Nurse Practitioner at a provider's office that knows more about cluster headaches than even the resident neurologist. Always talk to everyone you meet at your doctor's office.

G. Research

Oh so many gatekeepers. From FDA to the NIH for funding new research. it's always cheaper to say no. It is so expensive to conduct research that very few people or companies see a profit at the end of a long road when all they see are 300,000 possible customers and most of those don't use medications other than certain times of the year. Cut the number of customers in half or more because they are "only" in cycle and needing medications for 3 months out of each year.

Universities gather up all sorts of patent rights in the beginning and then sit on them until they are convinced that they will make money down the road. It takes a while and a lot of screaming to get them to dedicate their list of research teams to something that has a small patient population.

H. The list is long and I'll add more with future updates.

What you can do is help us educate all these gatekeepers. Go back to those that misdiagnosed you and tell them that they fell short for you and you hope they can properly diagnose the next cluster patient that walks into that dentist office, or general

practitioner's office. Don't be afraid to write an email to your past chiropractor's office. If we don't educate them, no one else will and someone else will join our community 20 years after being misdiagnosed by them.

The End, for now. Thank you for reading along

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