# Patient Profile of a Chronic Headache Suffer

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While the following document mostly describes the sufferings and treatments for CH (Cluster Headache); it also documents other forms of chronic pain that may or may not be related.

In many cases other pain and suffering have been related to the drugs and or therapies used to treat CH or the enormous amount of stress associated with the condition, raising a family, and keeping a job.

Headaches first began in 1997, where episodic, at most occurring once in the fall or spring, and often skipped a year.

Then in approximately 2004 headaches began to increase to a point where I now have chronic headache pain (or other form of pain) almost every day of my life.

Most pain can be described as physical but over time there has been an increase in emotional/psychological related pain that further complicates a balanced treatment plan.

With the right medications, most days' pain is manageable, while others I can not work, play with the kids, relate to my spouse, or function in any other productive capacity.

Finding the right balance of medications vs. side effects, exercise, proper diet, family health, mental health, and spiritual health continues to be an every day effort that requires trial and error; another source of stress that requires the help of family, friends, and several mental/physical healthcare givers.

## Pain Characteristics

I do get rebound and medication overuse headaches, but with the exception of headaches from PPI's, these headaches are minor in comparison to other head pain; ACETAMINOPHEN being the biggest culprit. **Never give ROZEREM to a suspected CH suffer.**

### Primary Head Pain

Pain typically begins in the evening roughly the same time each day, is unilateral and almost always on the right side, but on occasion will occur on left.

Headache starts out with short bursts of shooting pain that make there way back toward the ear. Pain is temporal and close to the eye but occurs in random locations. As headache progresses twinges became more rapid, deep, and sharp.

Eventually headache develops into a persistent pain around and behind the eye and will continue to increase in intensity. When this happens pain is deep, ongoing, dull, non-pulsating, and boring; onset of persistence, when it happens is rapid compared to precursor twinges that typically go on for several hours but may last for days or even weeks.

After pain has permanently gripped the eye or some region near it then it begins to spread out to nearby areas with perhaps a burst of deep dull pain high above the temple then one in the ear, maybe in the cheek, and or neck.

At its peak pain is only bearable by coving eyes and forehead with hands, applying pressure, and pacing, or rocking. Nose may be runny with clear substance and or eye burning and itchy, or red; may develop a deep persistent itching of inner ear. No noticeable visual or auditory aura and on occasion have experienced nausea with/without vomiting.

Twinges are random and increase in occurrence as headache grows to a crescendo and last a few seconds to minutes. Once headache subsides all pain goes away rapidly, always within the hour, overall a daily attack may last anywhere from 3 to 9 hours with several periods without pain and with persistent pain usually lasting not longer than 2-3 hours.

Headaches typically present themselves seasonally during fall/spring but are also triggered by travel to high altitudes, dry/cold climates, or sudden changes in weather. Headaches have gone into remission for several months or even years at a time but since approximately 2004 have been less than 1 month apart and quite often only days or weeks apart.

### Secondary Head Pain

Most background pain can be best described as pressure pain, think of it as the head being squeezed.

This may come on with a constant tightening and increased frontal pressure that starts out later in the morning about the same time each day and spreads to top of forehead or back of head; may be more dominate on right side but is often bilateral.

Sometimes there may be daily early morning awakening with deep, dull, and constant ache in back of head that worsens with increase in activity but goes away within the first or second hour of awaking; going back to sleep or trying to rest will only prolong the suffering.

At other times there is pressure between ears that causes noticeable short bursts of pain.

On rare occasions background pain may be throbbing in nature and sometimes messaging head or back of neck may help but this is typical not the case.

The degree and nature of background pain seems to change with each cycle and or cluster period. For some cycles I have more ear pain but no pressure related pain while there are even times when I experience neck pain that is right behind the lower jaw and hurts even more when I bend over.

## Maxillary and Gum Pain

Touching gum tissue behind and around 1st maxillary molar on right side of face triggers sharp jabbing pain lasting only a few seconds with residual throbbing pain lasting several minutes; this and a periodic persistent ache can make brushing around tooth difficult and can discourage chewing of food on that side of mouth. Sometimes have general ach in teeth and jaw not lasting more than a few hours at a time.

There have been times when several teeth along the maxillary on right sight will become extremely sensitive to the slightest touch; even allowing the tongue to touch these teeth will cause significant pain and discomfort. Pain will travel down into the lower jaw on the same side always starting with the teeth closes to the back of the mouth and work its way forward as sensitivity increases.

## Autonomic System Responses

Out of balance hormone levels, out of synch sleep patterns, and gastrointestinal complication can also be linked to clusters.

Still no explanation as to why testosterone is so low and why CSH level is not raised when it should be.

Disruptions in sleep patterns seem to be a major trigger/indicator of a cluster cycle. Interestingly I may even experience pain free cluster periods where I can not sleep at night then crash later in the day when my pain cycle world normal begin. The daily crash acts very much like a cluster, coming on fast, getting intense, and then leaving even faster than it came on.

Constipation has been a major problem and through vomiting have found up to 8 VIRAPAMIL in my stomach. I often have symptoms that match both IBS and Gastroparalysis; when following the eating recommendations for these syndromes then symptoms improve dramatically.

## Immune System Responses

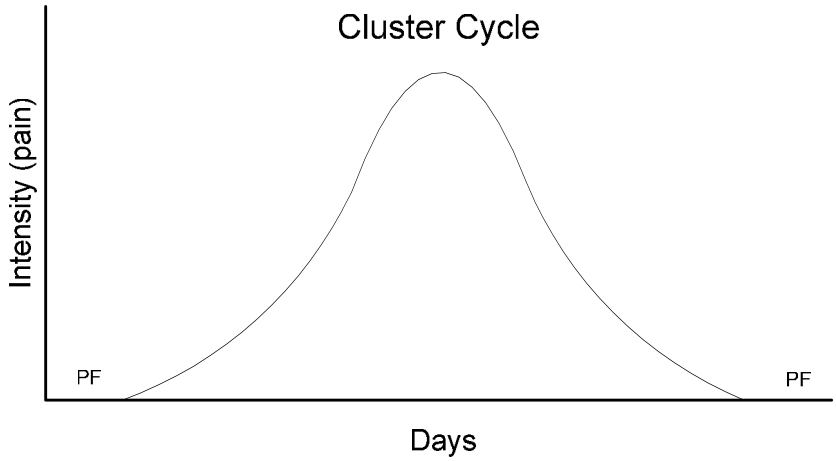
I have observed a connection between headache pain and pain associated with oral HSV lesions. Not only are these lesions extremely painfully, presence of a lesion typically signals (or triggers, I don't know) clusters. From the internet I have found data indicating that HSV1 establishes latency in the trigeminal ganglion. Perhaps this is why ear and jaw pain continues to be a complicating feature often associated with headaches. Perhaps an antiviral treatment may be a missing element to a more effective treatment of the cluster headaches.

## History

| | |
|---|---|
| **1997** | At age 28, may have had first cluster headache while on a fishing trip to Central Oregon mountains. Had runny nose and headache. Could not equalize pressure in ears. Came back next day and head was killing me. Stayed in bed for the night with runny nose, no fever, splitting headache; took Vicodin left over from wisdom tooth extraction and next day was fine. |
| **2000** | 1st maxillary molar on right side was crowned; symptoms indicated tooth had a microscopic fracture. |
| **2001** | Psychologist suggests that headaches are a result of stress and tension associated with a tendency to worry and over focus. And started working with Nurse Practitioner who put me on Zoloft. |
| **2001 – 2004** | Although not confirmed, TMJ dysfunction was suggested as possible cause of jaw and head pain; thus, after orthodontics consultation started treatment hoping for some headache relief. |
| **2004** | Approximate transformation date from episodic to chronic headache. |
| **1/04** | Root canal on 1st maxillary molar on right side. |
| **6/04** | Because I had a lot of nasal congestion and running nose decided to Install a whole house electronic air filtering system hoping that this may help with my headaches. |
| **5/05** | Extracted 2nd maxillary molar on right side. |
| **7/05** | Retreat of root canal on maxillary molar on right side. |
| **7/10** | Removal of residual bone spurs from 2nd maxillary molar extraction. Oral surgeon suggests Trigeminal Neuralgia and recommends seeing a Neurologist. |
| **7/15** | I see doctor to discuss increased headaches and dental problems. Use of OTC being as much as 8 TYLENOL and 8 IBUPROFEN per day for periods up to 4 days. Doctor suggests cluster headache. |
| **7/16** | Head CT without contrast unremarkable. |
| **8/05** | Doctor diagnosis's hypertension. |
| **11/05** | Head MRI with and without contrast unremarkable. |
| **12/05** | Official cluster headache Diagnoses from headache specialist and Neurologist. |
| **12/05** | Stopped drinking coffee. |
| **1/06** | At my request, doctor runs test to check hormone levels and discovers very low LH and no corresponding reaction in CSH level; thus, |

| | |
|---|---|
| | indicating dysfunction in testosterone production. T3 & T4 levels not known. |
| **2/06** | Doctor sends me to endocrinology and the endocrinologist puts me on hormone treatment. |
| **5/06** | Constipation, diarrhea, and vomiting have become extremely problematic. Thought to be the result of medications new evidence suggests a link to the cluster headaches. Headache specialist suggested gastroparalysis as common in Migraine. |
| **6/06** | A month of journaling shows a definite link to cluster cycles and gastrointestinal problems, limiting food intake, lots of fluids, and low fat diet become instrumental in managing constipation and elevating other symptoms. |
| **Up to 07** | Two months medical leave from work. Another cracked tooth that sets off period of heavy maxillary pain. No longer driving to Portland for work and change doctors. Botox and acupuncture. Working with a licensed psychologist. T3 = 136 (this is high). |

## Cluster Cycles




**Cycles Per Month**: dependent on cycle length but 1 to 4.

**Cycle Length**: 3 to 21 days.

**Clusters Per Day**: 1 to several per hour.

**Cluster Length**: 1 minute to 6 hours.

**Intensity Max**: 10 on pain scale (pacing, hammering, thinking about hospital).

**Intensity Avg**: 6 on pain scale (pacing, why me, waiting to get slammed).

**Intensity Min**: 3 on pain scale (tolerable for a while but thinking about meds)

Other than cyclic in nature the most pronounced feature is time of day clusters begin. Each cycle takes on its own exact time later in the day (late after noon or evening) and once established rarely misses its mark.

PF-Pain Free

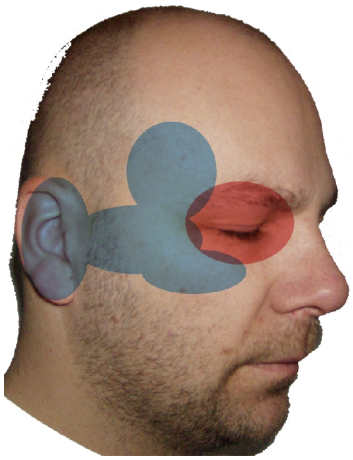
### Triggers

- Alcohol
- Sleep Disturbances
- Change in Atmospheric Pressure

### Indicators/Signals

- Single obstructed nasal passage not necessarily on side of headache.
- Single drippy nasal passage not necessarily on side of headache.
- Persistent itching of inner ear.
- Pressure equalization difficulties in both ears but most notably on side of head.
- Unusual or metallic like taste.
- Hot or burning sensation on side of head in, near, or around the eye.
- Watery eye.
- Itching and or nasal burning with some sneezing.
- Constipation.
- Cold sore outbreaks.

## Example



Earlier in day many precursor twinges close to eye.

By evening twinges become short bursts of deep shooting pain centered on right eye that at times travel back toward ear.

SAs headache moves toward crescendo twinges became more rapid, deep, and severe.

Eventually pain around and behind eye becomes persistent and starts spreading out with transient burst of ice pick pain; a deep shooting pain high above the temple, then one in the ear, or maybe one high above the cheek, and so forth.

8:00pm – Pain is persisting

10:00pm – 2 Advil, 1 Vicodin

11:30pm – Pacing

6 Hours 2 hours 20 min

*Pain permanently grips the eye: pacing & hammering*

1:00am – Triptan
2 Advil, 1 Vicodin

1:50am – Pain is backing off; can sit down now.

2:00am – Perhaps minor twinges but no other pain.

NOTE! The use of OTC's and Opiates for early and midway stage pain relief works well and unlike indications for migraine, taking a Triptan too early has no effect until entering later stages of the headache period (typically what I call the climax period). For migraine like headaches Triptans work as indicated, trex injection being the mostly likely to work.

## Prophylactic Treatments

### Acupuncture

Proved to be very relaxing; however, after six treatments had no improvement on headaches.

### Anti-Epileptics

DEPAKOTE (Valproic Acid)

At 1000mg at bedtime (500mg ER twice) and in combination with VERAPAMIL have achieved approximately 30% overall improvement in headaches. Thus far noticeable side effects are worth the improvement.

NEUROTIN (Gabapentin)

No noticeable improvement in neuralgia or headaches.

TOPAMAX (Topiramate)

At 100mg daily, no noticeable benefit – side effects included back pain, abdominal pain, difficulty concentrating, and bad taste in mouth when drinking carbonated beverages.

### Anti-Psychotics

SEROQUEL (Quetiapine )

What an awesome sleep aid. Prior to this was using large dosages of BENADRYL in combination with MELATONIN, at times also needed opiates.

### Beta Blockers

TENORMAN (Atenolol)

At 50mg once daily, provides the best control of hypertension. No benefit in preventing headaches.

### Botox

After 6 months of treatment no noticeable improvement in headache prevention.

### Calcium Channel Blockers

VERAPAMIL (Calan)

At 360mg daily approximately 10% improvement in reducing headache severity and frequency; less effective at managing hypertension.

### Magnesium Supplements

No noticeable prevention of headaches.

### SSRI's

ZOLOFT (Sertraline)

At 50-150mg daily it's possible that this may have had some prevention for the first couple of years of use. Headaches eventually became worse and I was completely taken off the medication as a possibility cause of the headaches. After going off there this medication there was no improvement in headaches; thus, ruling out this medication as a potential cause of headaches.

EFFEXOR (Venlafaxine)

Up to 225mg daily and no noticeable improvement in headaches.

## Tricyclic Antidepressants

AMITRIPTYLINE (Elavil)

At 25mg before bed time had no noticeable headache.

## Acute Treatments

### Triptan's

IMITREX (Sumatriptan)
IMITREX 100mg Tablets and 10mg NS are about equally effective; 6mg STATDOSE being far more effective than anything else ever used to abort a headache. Excluding the STATDOSE, using IMITREX at the earliest sign of headache does nothing, i.e., must wait until headache pain begins to persist. IMITREX vials and self injections are the best way to go, much of the time I can get two does out of a single 6mg vial.

MIGRANAL (Dihydroergotamine)
MIGRANAL seems to be slightly more effective than IMITREX Tablets and NS, but not as good as ZOMIG. Once again taking too early in headache development has no effect. A couple of annoying side effects are nasal passages getting plugged up for about a day and then I also get buzz like feeling.

ZOMIG (Zolmitriptan)
Compared to the IMITREX Statdose, ZOMIG is the next best thing in aborting headaches. May even work during early stages of headache development but only at the risk of using up a limited supply; thus, should wait to see if headache fully develops. A successfully strategy has been to wait for headache pain to persists or symptoms become intolerable and as a first attempt use the 5mg Zomig-ZMT then if two hours later still having problems follow up with a 5mg NS

### Analgesics

ADVIL (Ibuprofen)
With as much as 800mg four times daily can be very helpful at beginning/ending points in the cluster cycle. At this dosage can only tolerate it for about 3 days before it starts to give me stomach and intestinal problems; best to use the Solubilized form. When combined with high doses of TYLENOL and CAFFEINE can sometimes tolerate mid cycle pain.

BAYER (Aspirin)
Aspirin is actually quite effective against beginning/ending cycle pain relief. It is more effective at mid cycle relief than both TYLENOL and ADVIL combined. Unfortunately my can only tolerate this for about three days and then I need to use proton pump inhibitors.

INDOCIN (Indomethacin)
Not much better than ADVIL at 600-800mg and is hard on the digestive system, i.e., much like Aspirin.

OXYCOTIN (Oxycodone)
By far has been the best at treating low and mid cycle pain, i.e., shadows. Then if needed can use VICOPRFEN for breakthrough pain and IMITREX Injection for aborting full on hits, i.e., the beast. A single 20mg table daily works wonders against evening/night shadows while sustains opiate dependence without having to use as much VICOPRFEN.

TYLENOL (Acetaminophen)
Provides little to no relief and actually seems to extend the length of or complicate the cluster headache cycle.

## ULTRACET (Tramadol & Acetaminophen)

Is much more effective than any OTC for pain relief but not as effective as VICODIN; also, makes me feel buzzed and has Acetaminophen, not effective for peak cycle pain relief.

## VICODIN (Hydrocodone & Acetaminophen)

VICODIN is effective for low and mid cycle pain relief. Depending on the severity of a cycle and in combination with Triptan's also works well for peak cycle pain relief. While VICODIN with less Acetaminophen is slightly less effective in pain relief, more Acetaminophen seems to complicate the cycle, perhaps even extending it.

## VICOPROFEN (Hydrocodone & Ibuprofen)

Unlike VICODON, I no longer need to supplement doses with IBUPROFEN and it completely removes ACETAMINPOPHEN from the picture and has provided substantial improvement in quality of treatment.

## Other Treatments

### ANDROGEL

May help with hot flashes but nothing else of significance.

### BENADRYL

No apparent help in aborting a headache or shortening the cluster cycle but can be used to aid sleep; mostly helpful for cycles associated with nausea, dripping nose, and or congested nasal passage.

### CAFFEINE

When used in combination with ADVIL and TYLENOL seems to provide some additional pain relief.

### MELATONIN

Because my sleep cycle tends to get really messed up during a cluster cycle this can sometimes help me get to sleep.

### OXYGEN

Even with clustermasx and at 12 LPM for 15-20 minutes is at most a 50/50 chance at providing any relieve.

### PROTON PUMP INHIBITORS (NEXIUM, PRILOSEC, PREVACID)

Causes sever tension like headaches that can not be tolerated while coping with a cluster headache.

### ROZEREM

Slightly better as a sleep aid than MELATONIN in combination with BENADRYL but not by much. Complicates the CH cycle by significantly increasing clusters and I am no longer comfortable taking it; would rather struggle with lack of sleep vs. sever attaches that have been closely associated its use.

## Appendix A: Current Medications & Supplements

| RX | Medication/Supplement | Dosage | Time(s) Per Day |
|---|---|---|---|
| 1 | ZOLOFT | 50mg | MORNING |
| 2 | VERAPAMIL | 180mg X 2 = 360mg | |
| | ONE A DAY MEN'S FORMULA | 1 tablet | |
| | ACCUFLORA PROBIOTIC BLEND | 150mg tablet | |
| | FISH OIL WITH OMEGA-3 | 300mg tablet | |
| | | | |
| 3 | IMITREX INJECTION | 6mg Vial X 5 = 10 Doses @ 3mg | AS NEEDED |
| 4 | VICOPROFEN | 7.5/200mg tablets - 90 per month | |
| 5 | VISTARIL | 50mg tablets - 30 per month | |
| | | | |
| | ACCUFLORA PROBIOTIC BLEND | 150mg tablet | DINNER |
| | FISH OIL WITH OMEGA-3 | 300mg tablet | |
| | | | |
| 6 | SEROQUEL | 100mg | BEDTIME |
| 7 | DEPAKOTE | 500mg X 2 = 1000mg | |
| 8 | DIPHENHYDRAMINE HCL | 50mg | |

## Appendix B: Efficacy Chart

| Treatment | Prevention | Abortive | Pain | Sleep | Low Cycle | Mid Cycle | Peak Cycle | Sever Side Effect | Efficacy |
|---|---|---|---|---|---|---|---|---|---|
| ANDROGEL | | | | | | | | | 0% |
| DEPAKOTE | × | | | | | | | | 20% |
| IMITREX INJECTION | | × | | | | | × | | 90% |
| MELATONIN | | | | × | | | | | 10% |
| NEUROTIN | × | | | | | | | | 0% |
| ROZEREM | | | | | | | | × | 0% |
| OXYCOTIN | | | × | | × | × | | | 80% |
| SEROQUEL | | | | × | | | | | 90% |
| TOPAMAX | | | | | | | | × | 0% |
| VERAPAMIL | × | | | | | | | | 10% |
| VICOPROFEN | | | × | | | × | × | | 60% |

## Appendix C: Providers