

CARBAMAZEPINE

Drug Treatments for Facial Neuralgias

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Disclaimer

DESCRIPTION

Trade names include **Tegretol** and **Epitol**.

Carbamazepine is an anticonvulsant (epilepsy medicine) and is . generally the first medication to be tried in treating Trigeminal Neuralgia, Atypical Trigeminal Neuralgia and Glossopharyngeal Neuralgia. For typical TN, initial pain relief is often fast and quite adequate. Carbamazepine is so effective that it has sometimes been used as a marker for determining whether a patient has TN: if a patient does not respond to carbamazepine, then he probably does not have TN. However, this is not a completely certain marker. Carbamazepine may not be as effective for Atypical Trigeminal Neuralgia.

DOSAGES

Dosages are adjusted for each person individually, but usually vary between 200-1200 mg /day.

SIDE-EFFECTS

Carbamazepine is a dangerous drug if an extreme overdose is taken; death has been known to happen after very large overdoses. On the other hand, any drug is toxic when overdosed. If carbamazepine is used under a doctor's care, it is as safe as any other antiepileptic drugs. This does not mean that it is entirely harmless. The side effects can be unpleasant. When the treatment is begun, the side effects can include drowsiness, fatigue, dizziness, or nausea. (The nausea can often be partly controlled by taking the drug at mealtime). Extreme exhaustion and problems with memory and other mental activities are quite common. One of the most unpleasant and **debilitating** side effects is nystagmus (twitching of the eyes), which can make everyday life very difficult; however, nystagmus is a sign that the dosage has been increased too quickly, an should not be a permanent problem. Most of the other side effects should also pass once the body becomes used to the drug, which may take quite a while.

However, in the long term carbamazepine can have a variety of side effects. Various problems with vision may remain. A great many patients remain permanently exhausted and find their thought processes impaired. Memory loss is particularly common; since many patients are elderly, this is unfortunately often ignored as being due to dementia and aging. Nausea and dizziness is also possible. These side effects can be very unpleasant, and the patient should make the doctor aware of them. Having some side effects may be better than having TN pain, but the tradeoff is difficult.

There are two potentially serious side effects.

- **Rash.** If you develop a bad rash on taking carbamazepine, you should report this quickly to your doctor. The drug should then be stopped. It can be unsafe to stop an antiepileptic drug too quickly, so you should consult a doctor before you do this.

- **Lowered blood counts.** This can be quite dangerous and result in lowered **immune** system responses, for example. However, this can be monitored by routine blood testing every six months or so. In addition, very serious effects leading to death or disability are extremely rare. In other words, as long as testing is done properly, this is not something to be overly worried about.

MEDICAL REFERENCES

The professionals seem to have a somewhat mixed view of carbamazepine. All the literature we have seen is clear on the fact that carbamazepine is the first drug that should be tried. However, the side effects and long-term efficacy are matters that seem to divide the professionals.

[Walchenbach and Voormolen, 1996] say that "30%-75% do not obtain long term pain relief or experience side effects of the drugs". It is not clear what this exactly means.

[Browne et al., 1990] note that carbamazepine has earlier had a bad reputation because of its effects on the blood count. However, experience has shown that carbamazepine is no more dangerous than other old antiepileptic drugs. (This statement does not necessarily apply to new antiepileptic drugs appearing after 1990). The authors note that carbamazepine kills no more people than ordinary drugs such as penicillin do; in that sense, it is completely "safe".

[Tomson et al., 1988] note that carbamazepine may affect vision more heavily than older epileptic drugs (primarily phenytoin). Blurred vision is particularly common. The effect seem to be dose-dependent, but it is not clear whether stopping the drug will cause vision to recover fully.

[Hojer et al., 1993] report on cases of serious damage or death after very heavy carbamazepine overdoses. The effects of carbamazepine poisoning are very unpleasant, but large overdoses are required.

PATIENT EXPERIENCES

It seems that patient feelings toward carbamazepine are almost identical to the opinions of the experts: mixed.

Please keep in mind that the following comments do not represent a scientifically adequate cross-section of patients, and the quotes chosen may reflect the bias of the author. In other words, the information here may be skewed and faulty, but on the other hand it is the closest thing at the moment to "the voice of the people"....

Personal Experiences	
Based in part on Facial Neuralgia Resource's Personal Stories	
Share your experiences	
POSITIVE EXPERIENCES	
TN	"I use tegretol when there is pain, sometimes, when the pain is mild, as little as 1/4 of a tablet two or three times a day works. (That could be psychosomatic--a little security blanket.) I take the pills because even when the pain is mild and could be easily handled there is the fear that a big one can come because it has." - "Rizha": Comment: Even for a condition as serious as TN, the placebo effect might have some meaning, and even some patients may agree with this.
TN	"At 600 mg Tegretol, and building up. I'm nowhere near pain-free yet, but I can function and have hope" - "Dan"

"I have been taking Tegretol since 1979 for Trigeminal Neuralgia, MS. Present dosage is 1200 mg per day. If I forget to take it or am late, the left side of my face reminds me that medication is due. Generic products seem to lack efficacy. I am presently trying timed release pills with questionable results. I keep a bottle of fresh 200 mg regular pills handy to deal with pain break through. A regular fresh 200mg pill will block pain in 30 minutes from ingestion. Two 200mg pills will block pain in 20 minutes. Old pills don't work. My side effects are typical: fatigue, memory loss, blurred vision. An overdose puts me to sleep. My opinion: Tegretol is one of the great discoveries of mankind. I cannot function without it." - anonymous.

MIXED EXPERIENCES

TN	"The tegretol helped some, with the sensitivity of setting the pain off but did not have any appreciable effect on the pain. As my condition worsened [the doctor] increased my dosage but the Tegretol couldn't keep up." - "Tim". Comment: In many cases, carbamazepine is effective at first but the effect wanes out later.
TN	"Tegretol controlled the pain for about a year but I was often in a daze due to the high dosage I required." - Skip
TN	"...although the side effects were unpleasant it did provide considerable relief" This same patient later had to increase his dosage to 1600 mg/day, which "began to provide some relief, if you can call a zombie, half asleep with no short term memory someone who is relieved. It took ten days for that to subside."- "Rocky"
TN	"Tegretol makes one stupid, dulling the mental capacities noticeably. When I'm on the medication I find myself frequently grappling for the right word or phrase, and I'm always sleepy. But there's no contest as to which is the worse evil." - Greg
TN	"He prescribed Tegretol and just like that the pain was gone...but...the SIDE EFFECTS were lousy: dizziness, sensations of awkwardness, short term memory loss, to name a few" - "Gary"

NEGATIVE EXPERIENCES

TN	"Tegretol, worked almost immediately, but I had a drug reaction called Stevens-Johnson, which made it impossible for me to take Tegretol." - Mary
TN	"My blood counts dropped and I dropped Tegretol. I couldn't risk my blood counts dropping any further." Levonne

A few patients have suggested unofficial hints which may help to deal with the side effects.

- "...if you are having a bad time, get up in the night to make it the same number of hours between each dose." - Anonymous.
- "...also note that _everything_ interacts with tegretol..... remember even tylenol interacts with tegretol." - Anonymous.
- "I have found that the time at which I take my medicine is critical. The best is to keep my first dose at 8 or 9 pm and the second at 6 or 7 am. " - Anonymous.
- "My solution to the zombie period was to take 3-4 tabs right before bed thereby sleeping through it." - "Gary".
[Please note that some doctors might not consider this advisable].

LINGERING QUESTIONS

This section contains questions that the TNT authors have wondered and mused about but have

been unable to answer. Should we ever find adequate answers to these questions, they will be added to the sections above. We welcome comments and possible answers to these questions.

- **Drug Treatment vs. Surgery** - Many of the sources we have read have very differing views of carbamazepine. Surgeons seem to be most opposed and advocate surgery as soon as possible; neurologists are not so sure. This is not a problem in itself; medicine has and always will have differing schools of thought. Both schools have their points, and in any case time will show which one is stronger. However, does this mean that the answer you get will depend on who you ask?
- **Dosage Levels** - Many sources would claim that doses above 1000 mg/day are not going to provide any additional relief. However, our patient experiences tell of patients taking up to 2000 mg/day with no pain relief ["Julie"]. If you are one of these patients, should you perhaps ask your doctor to reconsider your medication?
- **Blood Tests** - Most sources recommend blood tests every six months or so. However, in practice not all doctors seem to agree, since the effects on blood levels are not as dramatic as was thought earlier. In practice, we know of patients who are never monitored. If you are one of these patients, perhaps you should raise the matter with your doctor? The blood tests can be somewhat expensive, but money should not be allowed to be a factor in something like this.

Downloaded from: <http://facial-neuralgia.org/treatments/drugs/carbamazepine.html>