

# 177 Copaxone Stories & Tips

I would much rather have first-hand statements than drug company info, as we all know drug companies can "sugar coat" the drugs they make.



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# TIPS FOR COPAXONE



Since I started injecting manually, I have had noticeably reduced injection site reactions. A friend of mine who was just diagnosed and was ready to give up on the Copaxone because of the site reactions just did the same (with the permission of her MS nurse) and is now able to stay on the drug because of it. To anyone who is having bad reactions, discuss with your nurse or doctor the possibility of doing the shots manually as you may be surprised at the difference! It's super scary, I know (I cried for an hour before I did it the first time) but it gets better. Just offering another possibility if the above doesn't help! Hope everyone's experiences are improved by the shared solutions advice.



Hi, I've been on copaxone for 5 yrs now and it has worked very well for me. I still get the reactions like yours but they soon go down if you massage the site you will find it goes down, I hope you get on well with the copaxone, Much love xxx



I know heat is bad for MS but you should try getting a hot shower right before the shot it makes it easier and it dissipates faster .....

Monique



Copaxone def helped me with a lot of my symptoms. Especially the numbness and my dizziness. I didn't realize it until I went off of it. Boy, what a difference it made for me!!! I hope you have the same success with it helping with some of your symptoms. Some of my symptoms went away and some of them did lessen. It's a daunting task taking a shot every day, but it is well worth it. Good Luck!!!



I've been taking COPAXONE ever since I was diagnosed with MS a few weeks after my 17th birthday. It'll be almost 2 years since I have been taking this medication and personally, I wouldn't

want to take any other kind. I have had only one side affect from COPAXONE which was the panic attack...but not to alarm you it does go away quickly. It's rare to get this side affect. In a way I like knowing I have a small chance of having a panic attack as a side affect then feeling sick the next day like some other medications. Don't worry, this is a good medicine!



I have been taking Copaxone for 5 years. I have not had a new lesion and don't get side effects. I have had the big knots at the injection site (on my arms) a couple of time. I would recommend Copaxone. I don't have to feel bad one day a week like interferons or get depressed.

The injections are easy with the autoject. I take it the same time every night so it becomes just another daily ritual. I don't have to fret about it. I usually take it out of the refrigerator a couple of hours before. (Copaxone now says it will keep up to a month at room temperature. So taking it out a couple of hours should be no problem and you don't have to worry about it being cold.) I hope Copaxone works well for you. M. Bad Ideas



I don't know how long you have been on copaxone but just so you know-- at any time you can become allergic to any drug not just this one... I was only on this for a week but I did notice sight reactions so I just stopped taking it. I was on betaseron for 4 years and though i never had problems with it I know other people have. Not every drug is for every person which might be why there are so many. if you are on it and so far no problems -- just be aware if you notice any coming up otherwise continue it and ask your neuro if you have additional questions. I have put in what it is to look for in case you notice any changes.

### Possible Side Effects

Side effects that generally resolve on their own and do not require medical attention unless they continue for several weeks or are bothersome: injection-site reactions (e.g., swelling, the development of a hardened lump, redness, tenderness, increased warmth of the skin, itching at the site of the injection); runny nose; tremor\*; unusual tiredness or weakness\*; weight gain.

### Unusual side effects that should be discussed as soon as possible with your doctor:

Hives (an itchy, blotchy swelling of the skin) or severe pain at the injection site. Possible immediate post-injection reaction: Approximately 13% of individuals using Copaxone will experience, at one time or another, a transient (very temporary) reaction immediately after injecting glatiramer acetate. This reaction, which usually occurs only once, includes flushing or chest tightness with heart palpitations, anxiety, and difficulty breathing. During the clinical trials, these reactions occurred very rarely, usually within minutes of an

injection. They lasted approximately 15 minutes and resolved without further problem.

**\*Since it may be difficult to distinguish between certain common symptoms of MS and some side effects of glatiramer acetate, be sure to consult your health care professional if an abrupt change of this type occurs.**

**You can become allergic to any number of things at any time and this is not only true of medication-- it includes food / detergents --you name it! just be aware if there should be any changes. as long as you know what you are looking for and how to take care of it, just continue on. Patricia**



**It is totally normal to have fears about possible medication reactions especially with this disease. I have been on Copaxone for about 6 1/2 to 7 years and the only reactions that I have had that were noticeable and were a little bit of a nuisance are shot site reactions BUT they truly are nothing compared to some of the episodes (one of them being called a whoppersode by me) that I have had. The shot site reactions are very treatable if you do things like rotate the shot sites and sometimes just massaging a little soap in the shower or lotion gently the area if it gets hard where the medication builds up under the skin, mostly just be kind to yourself and rotate rotate, rotate. Never use the same site more than once in a week. I have not had any new episodes in the time that I have been on it. I still have MS so the fatigue and residual disabilities from old episodes are still there, little reminders to just take it easy on myself. Rest assured sweetie it is great that you know about the possibilities with this medication. It is doubly great that you are doing so well with it right now. Just take it one day at a time (sorry for the cliché but it works) and pay attention to your body and stay hyperaware for any side effects that you may be having. Keep us posted if anything comes up! Send me an email if you want to talk more about this or anything. Keep rocking on baby...we are here for you :)**



**I was on Avonex for 2 years then they changed me to Copaxone. I was excited about the autoinject2 that came with it. I used it for about 6 months and decided to try my injections without it. It is so much better without it! It doesn't hurt or sting as much. The swelling and wheals are not as big and don't stay as long. I go straight in on my stomach and hips and at a 45 degree angle on my legs. I wish that I had tried this sooner.**

**If you are on Copaxone, you might try this. I know that everyone is different and it may not be the same for you, but the needle is so little it is very easy to do. I think the force of the autoinject2 caused a lot of the swelling and knots. Just thought I would share  
HUGS CHRIS**



I'm on copaxone and you DO NOT shoot into your vein. It's under your skin in the your fat, stomach, tops of your upper legs, hips, and the grandma fat of your upper arms.

They come to your house and train you when your on copaxone ( I don't about rebif) Copaxone is everyday shot, it hurts like hell but so does rebif (my friend is on it) um with copaxone there 's swelling around the injection site and it stays red swollen for a few days sometimes longer. You DO NOT have the flu like symptoms with copaxone rebif you do have them. If you can, use ice or a hot pack before doing your shot to help with the pain if you want. I find ice for 30 seconds before and 30 seconds after then and hot pack for 1 minute helps best. Sometime I don' even feel it. It just hurts worse when I'm sick or on my period. If there's any other questions feel free to message me.



Copaxone & Rebif are both administered via subcutaneous injection (i.e.: "skin pop") so no veins are involved... unless you have bad aim... or bad luck!!! I was on Copaxone for 2+ years and did no preparation other than swabbing the injection site with alcohol. MS has markedly diminished my tactile sensitivity so I barely felt the shots and had no real injection site issues!!! I plan to do nothing differently when I start Rebif next week... so long as there are no problems... KNOCK WOOD!!!!!!:^) BJO



Rebif and Copaxone are not taken in the veins. They are into the fat/muscles of your body. You do not want to inject either of these directly into a vein/vein (spelling?) If you hit a vein with any injection type medication, you are going to bleed. It happens once in a blue moon, but not very often. When you get prescribed the medication, you should be told by your neuro how to do it. Now for the injections, some use an ice pack, or a warm towel first. But that's to dull the pain, or keep the swelling down. So please, just remember. Your choice of meds, do not have anything to do with veins. If you need help, we are here for ya sweetie.

~~~~~Bubba



I tense my stomach before I inject my shot and for me anyway it doesn't hurt as bad as if I relax. Which most doctors disagree with me, but just an idea. Also as they said before - ice before and after help as well and take your shot at bedtime so you can sleep through any side effects/ flu like symptoms



**You won't have any flu like symptoms with Copaxone, and the shot is subcutaneous. You definitely don't want this shot going into a vein. They burn, but it's temporary 2 - 5 minutes maybe, use an ice pack for that... and your done! And did I mention there are NO FLU LIKE SYMPTOMS! I do mine at noon... by 12:15 I'm on my treadmill! One hint... the more fat you have in an area, the less the burn, I learned that the hard way!! Good luck Kim!!**



**Do the right thing... NEVER GIVE UP!**

**All I have to offer is a little personal experience.**

**I have been on Copaxone a little over three months. Not crazy about the daily shots but Yes the dizziness subsides from 8 or 9 down to 3 or 4 on a really good day. Please hang in there and expect things to gradually get better. Keep in contact with your doc's office. Don't be afraid to ask questions and expect answers of your doc. Be positive and stay strong! ((hugs)) Ersilia**



**I was on copaxone for 6 years and had no side effects, other than a red spot where I did my shots for a day or so. I did my shot right before bed. I did not use the backs of my arms. I used my butt instead. That was my favorite spot to inject :o) Good luck to you!! ~jen**



**I have been on Copaxone for 4 1/2 years. I haven't had any new lesions and the only side effect is a bump at the injection site sometimes.**

**It took me a couple of weeks to talk myself into getting started, but since I did I have not missed a daily injection.**

**I rotate between the injection sites though I skip the stomach site. I inject in my legs and my wife helps with the arms and hips. It just becomes a part of your routine like brushing your teeth. I take mine every night about 10:30. I just do it at the same time every day and don't fret about it. Mr Bad Ideas**



**I'm thinking a bit more about you and this post :) I hope that this is helpful to everyone that finds those "bumps" that Copaxone causes helpful. When I first started taking Copaxone I was told to use the ice pack prior to injection. Now they say to use the heating pad to open the skin/tissue/cells for the medicine. I've noticed that I have minor skin irritation now if anything at all. The heat or warmth is far better. It is also VERY important that you do move around in your injection sites.. How I do this is by going clockwise. Right thigh, right hip, right**

arm, left arm, left hip, stomach, left thigh & so on... Speak to Shared Solutions though. They will send you a booklet to give you the sites & other ideas. Write it on your calendar cause I know I'm forgetful :P Missy

Shared Solutions can also set up a nurse to come out to you to show you how to do the injection. The autoject (injection pen) is sooo much easier as well. They can obtain this for you by contacting your neurologist for you. I've never had to pre-medicate. Speak to your doctor before doing so.



I've been on Copaxone for 4 1/2 years now and I know exactly what you mean! At first I thought, oh my gosh, I have to go through this every day; how will I manage? But it does get better over time (even within the first week, month etc), both the pain and your ability to tolerate it. It never went away for me completely but while it does sting after, I can usually just ignore it. But here are also some things that have helped me with the stinging:

1. Warm up the syringe under your armpit or in your hand for 5 minutes prior to injecting. The closer it is to your body temp, the less it will sting.
2. Apply ice to the site after you inject to help numb the area. I used to do this, but don't anymore (no need).
3. NEVER rub the area after injecting. You can do this with other MS meds, but not Copaxone (it just makes it hurt more).
4. Inject as deep as you can. However, hitting the muscle is a very unpleasant experience so make sure you avoid that at all costs. In some areas you will be able to go deeper than others so adjust as needed. I went to injecting by hand for all sites except for my arms and I have never hit a muscle and I find that my site reactions have diminished greatly with this technique. Not everyone can do this (and I certainly never thought I could), but it certainly helped with my reactions.

Good luck and feel free to ask me any other questions about copaxone! I am happy to help.



After being on Copaxone for over 8 years now the 2 best things I can tell you are..

1. Take it out of the refrigerator at least one hour before you inject it. This will lessen the burning feeling.
2. The burning feeling after injection gets better over time. After a few months, I remember it stopped burning altogether. Good luck to you! It will get better, I'm sure of it.



I have been on COPAXONE FOR 3 years now and it really works for me..... I just remember that the 10 minute sting will go away soon,,,what i have been doing is putting pressure on the sting after I inject myself it calms it much faster...I will take it when I'm at my calmest point and that usually in bed I will Roll over onto a pillow so that the pressure on the site is a even stimulation soft but firm and it makes my 10 minute pain more like 3 1/2 and then I'm ready to go....I will usually have my cup of OJ near by and a light snake.....good luck jay joy



I have been on copaxone for a little over a year now. The bet tip that I can give you is to use warm hot pack and put where you going to do your shot for like a minute before and then use cold one for a minute after, you can put the hot pack back on for like 3 minutes after that. That's what shared solutions told me to do because I was having the same problem. its helps, also when I'm getting ready to start or on my period or sick the shots hurt worse. Just sharing message me if ya wanna talk or whatever

**ABOUT Immediate Post-Injection Reaction (IPIR):** I have had the whole reaction ONE time and it scared me. before i would just have chest tightness or shortness of breathe. IT SHOULD ALL PASS WITHIN 15 to 20 MINTUES.

The nurse told me before i started the medicine what to do if i had this reaction, and that is to relax and remember I can breathe even though it feels like I cant I can and to stay CALM and try to relax. YOUR NOT SUPPOSED TO ANYTHING AFTER THE SHOT, OR BEFORE THE SHOT EXCEPT BE RELAXED. SO TRY TO RELAX BEFORE THE SHOT AND AFTER. I KNOW IM SCARED OF NEEDLES AND FOR THE FIRST FEW MONTHS IT WAS HARD TO RELAX BUT YOU GET USED TO IT.

Also my nurse that came and trained me and my sister and my dad told me that I should never be alone always someone there incase something happens.

~Jamie



I was on copaxone. The welt is normal. Watch it and see how long it stays, and anything overly unusual. Big welts are supposedly normal. I got a red welt the size of a quarter and then is had a white ring around it about the size of a finger tip, and then the red welt again. then about 30 minutes later my entire leg turned into hives. I talked to shared solutions and they told me to call my neuro and stop injections. Try using either a heating pad or an ice pack after the injection. Another thing I did was let the injection sit out for about 20 minutes before the injection and it didn't hurt so bad. Do you have the auto injector??? If not call your neuro and look into it. It is much easier. Keep a diary to show your neuro. Neens

**You are in my thoughts and prayers. If there is anything else I can help you with let me know. Feel free to add me as a friend. Great big teddy bear hugs, Nena**



**I had the same reaction when I started copaxone... I even snapped a pic of the welt and sent it to Stan to post on the blog because it had me worried.**

**It is a common side effect to the shot... (injection site reaction) over time your body grows used to the copaxone and the welts are not as noticeable. The pain is a little trickier... I've noticed (more than once) that if I inject at the wrong spot or (gawd forbid) into the muscle it hurts like a mother! As Jaycee likes to remind us... \*deep masculine voice here ---->"keep a journal of your injections and note the good and bad spots" LOL Icing the area afterwards helps a lot with the pain and the warmth as well as the welts.**

**Make sure to mention the welt to you doctor at your next appt, just to be safe.... and you can call shared solutions @ 1-800-887-8100, Monday through Friday, from 8:00 a.m. to 8:00 p.m. (CT) to speak with a nurse. They can usually tell you if what is happening is a normal reaction or if you need to see your doctor.**

**Hang in there Girl. (((HUGS))) Chelle**