



F R I D A Y , M A Y 7 ,

Self Care for Steroid Withdrawal Symptoms or Adrenal Suppression

In trolling the internet for information, I haven't seen a lot of tips, tricks or techniques for coping with the aftermath of prednisone. So I thought I would share my steroid withdrawal regimen because I do think I would have ended up back in the ER without it. The endocrinologist I'm currently working with felt my self care was a Good Idea, so I hope that this info will offer some enduring value.

Of course, what works for me, may not for you. So use good judgment. Also, ideally, you aren't cowboying it like I am and actually have a physician taking good care of you.

It took me two weeks, 4 physicians, and an ER visit to get anywhere. So you may have to be kind of pushy if you think you have either steroid withdrawal or adrenal suppression.

1. Sugar, sugar everywhere. Corticosteroids can mess with blood sugar and cause it to crash. To compensate, I bought some Smarties candies and stashed them all over the place; my desk, my purse, at home, in the car etc... If I get hit with low blood sugar, I eat one roll and wait a few minutes, if I still feel bad, I eat another one and repeat as necessary.

Why Smarties? They are inexpensive, not too many calories, they store well and, because they are simple sugar, they are absorbed pretty quickly into the bloodstream.

If Smarties aren't handy, aim for junk food--stuff like full sugar soda, juice, candy bars etc...A healthier option that could be considered would be dried fruit or a trail mix of some kind. Just don't eat a lot. You don't need a ton of sugar, that will make things worse. Just a little bit.

I always follow the sugar with some protein to help prevent another sugar crash. There are usually almonds, peanuts or string cheese in my purse.

I am never without sugar and a protein based snack.

2. I ate on a regular basis whether I wanted to or not. Food helps stabilize blood sugar. Between the stomach flu and the steroid withdrawal, I had very little appetite, but I still ate. At least three meals a day (well except for when the flu was at its peak). Sometimes I even worked up enough interest to snack.

No special suggestions on what to eat. Experts say to aim for low

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L O S T I N



P A T I E N T

I'm categorized as a severe persistent asthmatic* and I have a history of HPA axis suppression due to steroids used to treat the asthma.

Doctors miss the HPA axis suppression every time and actively fight me on it. I've had am cortisols of 1 and 6 and ACTH of less than 5, yet

glycemic meals/low carb, but I have not had good luck with that. I found I needed a lot more carbs than usual to prevent low blood sugar, but this probably varies from person to person. Do what works for you.

However, I would suggest to always be sure to include protein in every meal because it helps keep blood sugar from going nuts. Carbs get blood sugar up when it's low, while protein helps keep blood sugar stable. You need both.

3. I napped. A lot.

4. I rested even though I didn't want to and didn't do much. I had no choice--the fatigue was overwhelming. So I guess my advice is don't plan on doing anything but sitting on your butt alternated with some heavy napping.

5. Salted my food especially if I was dizzy or light headed. I took this to mean that my blood pressure was low (I did have some 90/60 and 90/50 readings) and salt will help raise blood pressure. In between meals, good sources of salt are olives and pickles. Hot dogs are pretty high sodium as well and contain as much as 35-45% of the RDA for salt.

6. Took potassium, magnesium, calcium and B-complex vitamins twice a day. Potassium, magnesium and calcium helped with the muscle cramps. The B-complex was supposed to help with the energy, but I'm not sure it did. Still, B vitamins are good for the adrenal glands and neon pee is always fun. Make sure it has a good amount of Pantothenic Acid in it.

Note: This cocktail works well for me BUT coming off steroids can actually cause problems with electrolyte levels from what I understand as a humble patient. So if you take any of these supplements and feel worse, stop taking them.

Again, ideally, you have a doctor who is providing care and you don't need the internet's advice.

7. For pain, I took 800mg Advil, waited an hour or so and took 2 Tylenol. At night I used Tylenol PM. There were times when this was not enough to relieve the pain, but I just waited it out and the worst of it passed. Eventually, the stomach flu made everything worse and really aggravated the muscle pain for me, so your mileage may vary.

Also, it would probably be a good idea to run this past a doctor before trying it. It is safe for me, but it might not be safe for you.

8. I also used Benadryl to combat the inflammation. This actually was pretty helpful. I would not combine this with Tylenol PM at night as my understanding is Tylenol PM uses the same ingredient as Benadryl?

Might be good to check with a doctor or pharmacist on this as well. What I did was, on the nights that I wanted to take Benadryl, I used plain old regular Tylenol for pain relief. Or Advil.

9. I increased asthma meds to deal with the asthma flare induced by the steroid withdrawal. Mainly the Pulmicort (or Flovent if that's what you have), but the rescue inhaler saw some heavy use too. And the nebulizer was on the table at one point as an option.

In reality though, the Benadryl was the most helpful thing I did to combat the asthma. The inflammation was fairly significant in my case.

10. I did not exercise. I couldn't. I don't know how anyone would have energy to, but here's why I don't recommend it: The muscles are too prone to spasm (assuming you have spasms with your version of steroid withdrawal/adrenal suppression) which makes me believe an

the doctors still can't get on board. The medical myopia and general lack of adrenal knowledge is horrifying.

How did I ever get diagnosed? I took premed classes for 2 years (during a health upswing) and figured it out.

I thought since previous rounds of suppression have been so well documented, I wouldn't have a problem again. I was wrong.

I've been fighting the current round of Secondary Adrenal Insufficiency since March 2010. It has eviscerated my ability to work and to function as a normal human being. Which sucks since I have a toddler who just wants her momma to play with her.

*eh... I bet it'll go back to moderate persistent, once the excitement of last year's hospitalization dies down.

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injury would be really easy. I know that I was inordinately sore after trying to work out even while still on prednisone, which was deterrent enough for me.

So I would not worry about getting physical while in the throes of steroid withdrawal. If you must, keep it really simple, low impact and don't go so far from home that, if you crash, you can't find your way back.

11. Keep looking for a doctor who will take your symptoms seriously. Once you do find that doctor, obtain ALL copies of any test results related to your condition and keep them for future reference.

In my case, the last time I had adrenal suppression was over 10 years ago and, while some doctors could find the test results in the computer, others said they weren't available due to age. So keep your records--you're going to need to present proof if this comes up again in the future.

12. Insist on an consult with endocrinology if you go to the ER. Or have your family do it on your behalf if you're incapacitated. Alert the ER that you think you're going through steroid withdrawal or perhaps have suppressed adrenal glands. Be sure you know your prednisone dose and its history, they'll need that.

If you are sick enough to go to the ER, don't leave until an endocrinologist has been consulted about your case--that should be the one specialty that will know what to do (and even then it can be a crapshoot). This is especially important if the ER is showing no signs of sending you home with low dose steroids to support your struggling adrenal glands.



POSTED BY AALI 1M : 03 J4 A VA M
REACT funny (0) interesting (2) cool (3)

LABAEDISENALSUBDESESSU
PREEDNPIRSEODNNEISONSETWRDHRWA

4 3 COMMENTS :

Jan September 13, 2011 at 7:44 AM

Thank you for the help. I am just starting my withdrawals today. Been up since 2 am could not sleep the pain and spasms in my legs and joints were sooooo bad. Feel like my ankle is sprained and my knees are broken. All swelled up. Could barely walk this morning. I was all shaky too.

Still waiting for all the other symptoms though. Started taking the steroids because I had an allergic reaction to some meds. I'll never take prednisone this long again - been on it for a week now and am winding down and have 2 days left. So that should be real fun. Your post is the only one I've found (and I'm SO glad I did!!) and I will follow it to the needs that fit me. I do appreciate your effort with getting this out there. And I can appreciate the pain you went through - I know it was NOT fun.

I hope it all worked out for you. As I do me.

Thanks,
Jan :)

[Reply](#)

Anonymous September 30, 2011 at 10:32 AM

Thank you for your post. I have Hypopituitarism that reduces my adrenal function. I have a new doctor that wants to retest me for everything, but that means getting off the hydrocortisone that I have been on for almost a year. I started

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11 hours ago

out on 20 ml and am now off after about 2 weeks. I still feel like crap and hope that I will be able to function again soon.

[Reply](#)

Anonymous December 3, 2011 at 4:24 AM

Tapering off low dose cortisol for adrenal exhaustion and have terrible back pain - especially mid/lower. Tried everything - pilates terrible idea and used a heating pad last night and now in agony. The only thing that helps is ibuprofen. Adrenal inflammation?? Have work to do and will probably go back up a little today and through December. On low dose cortisol(not prednisone) but enough to suppress adrenals.

[Reply](#)

Anonymous January 15, 2012 at 5:32 PM

Thank you for th post. It was very informative and answered a lot of questions i had. I had a horrible time on steroids and just as horrible time getting off them. I had horrible side effects while on them and was exctemely tired and had no energy when i went off them. I think these drugs are horrible and people should be made aware of what they can do before taking them.

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Anonymous June 12, 2014 at 11:03 AM

I absolutely agree. The cure is worse than the disease.

Anonymous June 12, 2014 at 11:05 AM

How in the world do you cope with all those problems? I can barely function with colitis and neuropathy with steroid withdrawal.

[Reply](#)

Anonymous February 22, 2012 at 2:09 AM

Thank You so much for sharing this info ... I was misdx'd as having Addison's 3 yrs ago b a quack endo & am just finding out, so I have Secondary Adrenal Insufficiency. My new EndoC thinks there's a chance my adrenals will "wake up" ... 50:50 likelihood. BUT OMG! the withdrawal is horrible ... every time we get to the second stage of the dowsing, I am finished OUT ... FINÉ. In addition to all the symptoms you mentioned, during the evening, thru the entire night (this is the dose that is being messed with), I constantly go back & forth from chilling to breaking out in a profuse sweat from chest on up to scalp & will be dripping, then in less than 5 min, chilling again. My body temp runs from 96.5 - 99.9 & I'm an absolute mess. I don't believe I'm being tapered properly. How did you taper? My dose if Hydrocortisone is 20mg am & 10mg pm (4:30) My taper dose is down to 10mg every 48 hrs on pm dose & am is still the same. Am also on a Gastric Jejunem feeding tube for Chronic Pancreatitis, have Gastroparesis, Eosiniphilic Esophagitis, Fibromyalgia, Hypothyroidism, Chronic Daily Migraines, & Asthma. Yes, THANK YOU DR! for adding secondary adrenal Insufficiency to the list. :p

~cnspts

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Brandy Hofmann August 11, 2012 at 2:58 PM

I was given 250 mg of prednisone and it suppressed my adrenals. I started taking 15 mg of hydrocortisone and tapered off 1 mg a week, this is key !no matter how high you are . The higher you are you are say 75 or above you might be able to say do 5 mg one day and not the next but when you get down to 30 and below you should taper 1 mg a week, it is a pain I know but.... I had to go back up because I went to fast. I usually stopped a couple weeks at 25, 20 and especially at 15 and took adrenal support to see if

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adrenals
wake up? Don't go down too fast after fifteen maybe half a mg a week until you are sure they are producing or you will end up in crises like me. By the way, Er doctor shot me up with prednisone after I showed him my medic alert that said 50 mg of solou Cortef injection for emergencies. Know your stuff. Cortef is the Brand name for hydrocortisone but it is stronger, when I took it for a month I couldn't sleep more than two hours a night for over a month. so I statred tapering over to hydrocortisone. like switching to 20 Cortef and 5 mg Hydro and then next few days 5 more I did crash but not in hospital. Cortef is mineral based stays in body longer, hydro is obviously water based. Do A saliva test when you are at 15 mg only reliable source the guideline for blood tests are not accurate unless way low.or way high. Most endocrino Drs don't believe in this but it is sound instead of messing with drugs that will kill you the rest of your life. If need to find a Naturepath or a holistic DR. that can help. Also Hormones hide in your tissues so hard to get a good read with blood tests even if you are not afraid of needles and 24 hour urine a good start but before you go all the way do a saliva test! test your DHEA , ACTH and other Hormones also as they take up slack for your adrenals and i they may be low. especially DHEA.

[Reply](#)

Anonymous [March 13, 2012 at 5:01 AM](#)

feeling better knowing that shakes all over the body ,tiredness and aching limbs are all part of coming off steroids.Thought I had some terrible illness that would need adoctor soon.I was only on them for 5 days 40mg a day didn't expect this when I stopped. thank you so much for informing us. regards katrina.

[Reply](#)

Anonymous [August 17, 2012 at 12:45 AM](#)

Thank you for your info I was on 40mg for over six weeks due to viraemia(insect bite related virus) I am in Australia was supposed to taper 21/2 mg every five days got below 5mgs and had dreadful withdrawals so upped to three quarters of 5mg
Prednisilone is a great drug for emergency however should be discontinued as soon as possible best wishes to you all

[Reply](#)



JC Jones [October 1, 2012 at 8:47 AM](#)

Thanks for your post. I have joint pain where I never had it before I went on predizone. It was the only thing to take for PMR and it was great. My pain coming off is not as great as the pain it suppressed but I do wish my body would kick back in. I have been off for over a month am still having withdrawal symptoms On one told the about steroid withdrawal syndrome, I had to do a web search to find out anything about it.

[Reply](#)

Anonymous [October 20, 2012 at 4:25 PM](#)

Was given over 15 steroid injections in 4 months, by 3 different drs. Majority of shots, from one pain clinic. Had severe adverse reactions after last injection. Went from myopathy, neuropathy, cushings, you name it I had it. Then, noticed sudden bouts of severe weakness hitting me. Felt like I was dying. Saw several drs, all said they didn't know what it was. Almost gave up. Found a new dr. She diagnosed me with steroid withdrawal syndrome. Had never heard of this before. Did my homework...cannot believe, to date, how many drs are uninformed & unaware of this syndrome. I am going into week 7. I have had every listed symptom. I'm still weak, the crying & anxiety is off the charts! I'm so dizzy & I've been to the e/r 6 times with myalgias, arthralgia, nausea, pain in my body like no other. My scalp hurts, my hairs falling out, my skin feels burned, my skins peeling (severe dry skin). I'm either hot/cold. My Lord, this is poison. And, drs give this stuff out like candy in the US. I cannot believe how sick I am, I cannot handle normal stress w/o feeling like I'm going to pass out. My thyroid, magnesium, potassium, were all affected by the steroid

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injections. My cortisol levels have been normal (weird) and the dr tried to put me on 5mg of pred but I reacted. I'm over the insomnia. It's awful. My hearts with you all.

[Reply](#)

Anonymous [January 15, 2013 at 4:41 AM](#)

I have been on Prednisolone for 18 months due to Polymyalgia. It worked as far as the polymyalgia was concerned but I am now taking 2mg and am due to reduce to 1 mg in February. I feel awful, I am permanently tired I have aching legs& arms and just want to sleep all of the time. How long will this last, my endocrinologist wasn't much help only told me my adrenal glands were coming back up to speed and to be patient it would take time. Wendy

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Anonymous [February 23, 2014 at 6:09 PM](#)

I also have been taking Prednisone for a long time and finally have weaned off of it. I started because of Polymyalgia and found that when tapering off, I also got off of wheat products (gluten free) and the joint pain disappeared as I was tapering. You might consider trying that.

[Reply](#)

Anonymous [January 15, 2013 at 8:57 AM](#)

I was taking a daily asthma medication which was a steroid & Flonase nose spray which was also a steroid. I ended up with Cushings disease, which was horrible. My doctor couldn't believe that the small steroid doses in each of the medicines could cause Cushings. I went to the endrochronologist and after looking at the list of drugs I was taking, he said to stop the Flonase & the asthma medicine. The drug Truvada that I take increases the steroid dose enough that it gave me Cushings. As soon as I stopped Flonase & asthma medication the Cushings started to recede. However, I ended up with Steroid withdrawal including muscle & joint pain, exhaustion, not being able to sleep, and severe hot & cold body temps. It is now been 3 months since I've been off the steroids and I still have all the withdrawal symptoms. Its just awful.

[Reply](#)

Anonymous [January 28, 2013 at 5:40 AM](#)

Thx u so very much for sharing your info. No one told me about withdrawals. Had to go thru several pages on net bfor found u. Even tho I feel horrible at least hav kind of peace of mind & not so scared cuz of your info. God bless u. Kay

[Reply](#)

Anonymous [January 31, 2013 at 9:22 PM](#)

Thanks for your comments. I was on Nasacort for sinus issues and have had severe steroid withdrawal since I started a taper in October. Nightmare anxiety, panic, muscle pain, nausea, weight loss, dizziness, low blood pressure, heart palps, crying, body vibrations, extremity numbness, headaches, and inability to deal with stress of any kind. Terrible. I just have to wait for it to pass. Doctors should be more aware of steroids in any form - I never thought this was possible from a nose spray!!!

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Philippa Brown [August 15, 2015 at 8:44 AM](#)

Hiya, just a quick question but did the vibration feelings stop!??? I'm having them at the moments, has lasted a month since coming off the steroids :(

[Reply](#)

Anonymous [February 2, 2013 at 10:15 AM](#)

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I feel so relieved after reading your article. In early December I was diagnosed with candida albicans infection of the esophagus caused by use of inhaled corticosteroid inhaler for past 12 months as treatment for emphysema. The doctor who diagnosed the infection was gastroenterologist followed endoscopic procedure. With this knowledge I called my pulmonologist and asked the doctor to prescribe a non steroidal inhaler, with no warnings offered the doctor approved a prescription for the non-steroid inhaler. I immediately dropped the steroid inhaler and began using the non steroid inhaler. Almost immediately I began to have severe right knee pain that spread to my upper thigh and into my hip then down to my lower leg and ankle. In addition I felt nauseous, experienced severe sweats (dripping down the back of my head) frequently, was unable to get out of bed for two days due to extreme fatigue; the list could go on. Saw my internal medicine doctor and expressed concern that the candida infection had become systemic. Was sent for leg X-rays, a Ct scan, and blood tests along with referral to infectious disease specialist. I saw the specialist who assessed the test results and was told that I did not have a systemic infection. My internal medicine doctor commented, 'well, you know how you are'. The following week saw my pulmonary doctor for routine 6 month check; explained my symptoms to this doctor who responded saying that I seemed to have constitutional symptoms and perhaps my body was reacting to one of the medications I was on. Today, two months since dropping the steroid inhaler my pain has spread to both legs, hips, and my back; I limp like a frail elderly woman of 90 (I am 60 and previously fit and active) continue to feel very weak, tired, and increasingly depressed not knowing what is happening to my body or if my body is failing. I am well educated and until this began was enjoying my work in the first three years of a career change. From what I've read above I gather that I need to be looking for a competent endocrinologist?

[Reply](#)

Anonymous [February 17, 2013 at 6:15 AM](#)

Steroids of all forms are dangerous. Am getting all sorts of withdrawals and adrenal suppression symptoms from applying potent topical steroids on my face for acne which it isn't for. I went to the pharmacy for an acne cream and the pharmacist gave me a steroid cream called betamethasone valerate. However it cleared my acne but always had a more serious relapse when the creams finish so I always went back and got a new one. I used these creams excessively for a year until I woke up 4 months back with a severe headache with head pressure and fever. Went to the doc, he did a couple of tests and found nothing. That's when I started suspecting the steroid creams and stopped them instantly. Since then I've been having low blood pressure, lightheadedness, dizziness, abdominal cramps, nausea, leg and arm pain, muscle aches, poor concentration, frequent urination, sometimes my body feels very hot and sometimes very cold, am very depressed.. etc... but what makes it more worst is that all the docs I've been to don't take me seriously, they think I have anxiety. How can I have that if I was living a happy non stressful life before suddenly waking up with all this? So you see unlike most of you guys I am alone in this. POOR ME!! :(... anyway I'll just keep praying and hope that this all would go away bc I heard hpa axis recovery is slow and might take up to 6 months to 2 years. I'll rather suffer with pain rather than going back to taking steroids.

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Anonymous [October 7, 2013 at 8:07 AM](#)

I don't want to say it's wonderful to read about your pain, but I have been where you are, and thought I was going crazy. Used a corticosteroid ointment for 8 months - prescrip said "as needed" so I never bothered to read the small print that said "two weeks only." Stopped using it when I had three separate episodes requiring adrenal efficiency, and just went flat - nausea, vomiting, unbelievable malaise. And I have never taken meds, and am a very healthy 62-yr-old. But the recovery has been an arduous journey - endocrinologist, neurologist, 2 ER's, dermatologist, dentist, ENT doc, you name it - I have been there, and everyone said it was in my head. I've never been so sick, and at times would just cry wondering if I would ever get to the other side of this. It has been three months, and I just spent my first weekend where I didn't at some point need to curl up in a ball, or cry, or feel too lousy to participate.

Please

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► [April \(62\)](#)

F T C D I S C

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T O T A L P A

Thank God every day for a supportive husband who didn't think I was nuts. I will never use another steroid as long as I live - I would rather die than go through this again!

[Reply](#)

Anonymous [February 25, 2013 at 8:16 PM](#)

A great article, thanks so much! I have Crohn's and am finally tapering off prednisone after 5 years (recently switched to dexamethasone). I have been trying for 3 months now and I get down to a certain dose and the body pains and other symptoms become unbearable so I have to bump up a bit and try again. My GI is trying to manage this but I'm going to request a referral to an endocrinologist. I have done much sleuthing on the 'net and I have learned that this can take up to a year to reactivate the adrenals. It can be done without feeling too terrible, i.e. if you feel like you can't function, then your dose is too low. This is going to take time and patience. If the body gets too sick and stressed, then there is too much strain on the already fatigued/atrophied adrenals to start working again. I've learned this the hard way!

Good luck! To the person who posted above mine, this can be confirmed with an early am cortisol blood test (before you take any steroids that day).

[Reply](#)

Anonymous [March 28, 2013 at 7:59 AM](#)

My husband is a physician suffering from all sorts of complications after a year on Prednisone including two taper attempts--the first nearly killed him with an adrenal crisis. You definitely need an endocrinologist working with you and insist on being monitored closely with blood work done frequently. Does anyone have any thoughts or suggestions on home to go the alternative route in conjunction with conventional medicine?

[Reply](#)

Anonymous [July 7, 2013 at 5:21 PM](#)

I have been on 60mg for 5 years, 5 days ago I decided to just stop and deal with side effects, so far just vomiting, diarrhea, weak, shakes, fever, joint muscle pain. Hopefully it don't get worse

[Reply](#)

Anonymous [August 4, 2013 at 6:33 PM](#)

Tapered from 60mg to nothing over the last year and a half. Have been super low on energy and just feel like laying down. Have found useful an adrenal support herb / tonic Astragalus. Also an energizing and hormone balancing herb Maca.. Blessings, Keth

[Reply](#)

Anonymous [August 12, 2013 at 8:18 PM](#)

Thank you for this information! Although I have been feeling AWFUL for about a week, I feel BETTER just reading that others understand and many have the same symptoms. I have Crohn's and had been taking dexamethasone since March. Even though we attempted to taper the withdrawal in several different ways, I stubbornly have refused (so far) to go back on them despite the fact that my joints hurt, I am nauseated, not sleeping well, depressed, and having periodic abdominal pain. Fortunately, though, the abdominal pain is not severe. Ten days ago, I took my last steroid dose, and since then I have trouble getting through the day as I have virtually no energy, and I hurt all over. My doctor thinks I should start taking the steroids again, but I do not want to do that. Thank you to everyone who posted here, and for the provider of this website. Just knowing there are others who are experiencing the same symptoms makes this bearable.

[Reply](#)

Anonymous [August 22, 2013 at 1:58 AM](#)

I am tapering my prednisolone 1mg every two weeks. My

problem is I have developed a rash all over my arms. Tried different creams from doctor but still there. Am awaiting results of blood tests now. Has anyone else suffered with extremely itchy rash similar to hives? Could this be a symptom of steroid withdrawal?

[Reply](#)

Anonymous [October 27, 2013 at 10:21 AM](#)

Have been on prednisone for over 10 years, on average 15mg per day, due to adult onset asthma. Have tried to taper numerous times, without success. Once I got down to 10 mg, the symptoms re-appeared. Finally, am on Advair, Combivent, and Singulair, while tapering down in increments of 1mg per week. Am down to 5 mg, without asthma symptoms. However, my joints and muscles ache., but its tolerable considering the alternative. I'll continue the tapering to get off this stuff. It's wreaked havoc on my skin over the years, and who knows what else.

[Reply](#)

Anonymous [November 3, 2013 at 6:36 AM](#)

Anonymous - November 3, 2013

Thank you so much for the information. I am currently going through prednisone withdrawal. I took 40 mg./day for four days after being in the emergency room for a drug allergy. I had no idea how horrible the withdrawal would be. I am so relieved to know I am not going crazy. I wish the doctors would advise you what could happen.

[Reply](#)

Anonymous [November 12, 2013 at 5:11 PM](#)

What a bunch of uneducated idiots posting here. "I went from 60mg of prednisone to just stopping and dealing with the sideeffects". I wonder if that dope is still alive. SLOW WINS THE RACE PEOPLE. Why deal with the horrible side effects, including death, by tapering by large amounts quickly. They make 1mg tablets. USE THEM! I'm taking over two years to properly withdraw off of prednisone (was taking 40mg per day for 15 years). You won't find me in the ER...

[Reply](#)

▼ [Replies](#)

Anonymous [May 10, 2014 at 11:39 PM](#)

Some "idiots" have no choice im afraid. I have a lymphatic cancer which the steroids are masking. I have come off high dose of steroids to find out wot cancer I am dealing with. Im no idiot given a choice would come off them slowly. So plz think before you make a sweeping statement like that.

[Reply](#)

Anonymous [November 15, 2013 at 12:20 PM](#)

Thank you so much for this post. After reading the post here, I feel i am not alone in this situation. These doc are crazy. When I told my doctor about the side effect I was under going after taking this medicine. Instead for asking me to stop talking the medicine she told me it was not the effects of medicine. She sent me to get tested for thyroid. She told me I was getting anxious about work/family etc. which is totally false. who does not have issue/ anxiety or stress about work/family. The day I stopped talking this medicine I had muscle cramp all over my body. This is one crazy medicine. I hope ppl who are facing with same issue get well soon. Be strong and positive.

[Reply](#)



Joey Brown [December 4, 2013 at 10:10 PM](#)

Wow, I happened to come across this blog when searching for endocrine help with topical steroid withdrawals I'm still enduring after 40 months of cessation from them. I also did take low dose orals for about a month during the topical withdrawals and am having pretty intense muscle and bone

pain in this stage of the withdrawal. I was a hot mess in my skin for 27 months and have had dry eyes as well. I belong to a group called International Topical Steroid Awareness Network and manage the forum which is growing daily. We want to raise awareness of this problem as so many in the medical profession overprescribe steroids of both types. You can cold turkey off the topicals but for sure have to taper down on the orals. I feel for all of you and hope you make it through okay. I'm probably going to have withdrawal symptoms from the topicals for a while yet since I used for so many years unknowingly. My skin is 90 per cent better but still have upper legs cycling. We have many in the forum who have done the orals as well and are having it rough. Thanks for having this blog to help others! We have about 50 members with blogs as well. Hang in there everyone! xx

[Reply](#)



loren mccormac December 4, 2013 at 10:26 PM

My son has been going through topical steroid withdrawal for 21 months, it has been so terrible. Thank you for your blog...seems the symptoms are similar, except for the red skin syndrome.

[Reply](#)

Anonymous December 19, 2013 at 7:26 AM

I have been on prednisone for over 15 years. Avg dose 10 mg daily. I am tapering off and am now down to 5mg. Starting to feel the joint aches and sinus problems. It appears that some of these symptoms are common. I am glad I found this blog.

[Reply](#)



S January 1, 2014 at 5:04 PM

My 7-year old daughter has been on courses of high-dose Prednisone and Dexamethasone as treatment for her T-cell leukemia. I read her the tips and the subsequent posts, and she found comfort in hearing about people with similar symptoms and possible treatments. She has found heating pads and narcotic pain medications to be the most effective, partly because she cannot take regular antiinflammatory medications due to blood counts. Thanks for the information!

[Reply](#)

Anonymous March 3, 2014 at 12:46 AM

I think I am going through steroid withdrawal after stopping fairly low-dose asthma inhaler and nasal spray. I've been on these daily for the last year, and a few times a week for three years. After just a few days off, I am so exhausted that I can barely keep up with basic things like showering and brushing teeth.

I have thought about going to the ER tonight. I do have an appointment with my regular doctor in two days. I will be asking her to refer me to an endocrinologist.

It's funny, but I wonder if my asthma symptoms the last couple of years were the first problem to surface as part of a larger adrenal problem. I have been under immense stress due to job loss and underemployment the last several years and I can remember an episode of heat exhaustion improved by taking salt, sometime back, that I now wonder if I should understand as related to an underlying lack of cortisol.

It's so confusing and really scares me, as I do not think my doctors have a clue. Instead, I just get medication thrown at individual symptoms, rather than a potentially underlying condition being diagnosed and treated.

I hope I can get help. Thanks for this blog.

[Reply](#)

Anonymous March 8, 2014 at 1:48 PM

Took Pred Forte (prednisolone) eye drops for 3 months. Tapered off for 4 wks and the last week was absolutely horrible. Barely functional at work especially with any stress, difficult to be in a moving car, confused alot, elevated anxiety, and lots of abdominal pain. I heard the lower dosages are some of the hardest to completely ween off of. It definitely applied to me.

[Reply](#)



Splodge May 8, 2014 at 2:52 AM

Just adding to all the thankyou's for this post. I'm down to my lowest dose of pred. in about 18 years: 5.5 mgs, due to a new medication regime for my Crohn's Disease. Prednisolone use has been necessary, but not without many many problems, so I'm delighted that I can reduce.

However, I found you via Dr. Google when I was trying to work out if a reduced prednisolone dose could be causing anxiety/inability to tolerate stress to an unusual degree. From what I'm reading above, it seems it *might* be due to blood sugar crashes. Do you think I might be on the right track here?

[Reply](#)

Anonymous May 15, 2014 at 12:01 PM

17 yr old daughter with IBD UC/colitis...had recent flare and took prednisone 40 mg for two weeks and then began tapering 5 mg each week...she is now at 25mg per day...miserable and seems to have also caught a virus (lost voice, vomiting, cough) but the worst is the severe fatigue, body aches all over and little relief from Tylenol (cant take ibuprofen due to UC). Wish we knew if it was stomach virus, steroid withdrawal or adrenal insufficiency. How do you know?

[Reply](#)

Anonymous June 12, 2014 at 12:22 PM

Has anyone had bad reactions when going off of Budesonide/Endocort? I have been on it for 10 days for microscopic colitis and am trying to taper with horrendous results.

[Reply](#)



Dave Diamond August 30, 2014 at 4:12 PM

I was convinced by a doctor 3 years ago that I have secondary adrenal insufficiency, and he put me on hydrocortisone. After 3 weeks I was so sick I no choice but to stop it. I was never the same again; I went from having relative minor problems to being essentially housebound.

But I would give anything to merely just be housebound again... it gets worse... now three years later I developed what we thought was a sinus infection, and the ENT told me to take Nasacort. I knew to avoid steroids, but I was ASSURED that these stayed in the nasal cavity and did not enter the bloodstream. I double checked with another ENT and two pharmacists. They all said the same thing... it doesn't get into the bloodstream. So I took it.

Lies, lies, lies. It turns out that it DOES get into your bloodstream -- just not enough to bother HEALTHY people. I am more than a pissed off patient at this point. My life is essentially over. It's been almost 3 weeks now since I stopped it (I only used it a couple of days) and I have been barely able to move ever since. Muscle spasms that I never thought I could imagine. I cannot function at all, and I have been pushing through things for years that would make 99.999% of people crawl into a ball in the fetal position and stay there. If I say it is impossible, it actually is.

My wife has stage 4 cancer, and I needed to care for her; she has a big surgery scheduled in 5 weeks. Now she has to care for me instead, as we have no support system (health problems will do that to you) which means we are going to get sucked into a vicious cycle that we can't get out of.

And there is nobody to even "complain" to about this, because don't you know, steroids CAN'T do this to you! Especially ones you just put in your nasal passages! It just doesn't happen, that's what all the docs say. Yet..... it does.

We are now preparing for end of life issues for both of us. It shouldn't have been this way. I was a relatively healthy person whose health has been stolen from me BY the medical system. And without being able to care for my wife, she can't get help either. So the medical system has taken both of us. Beware... stay away from it unless you will die otherwise.

[Reply](#)

Anonymous July 9, 2015 at 4:36 PM

Great article. Smarties are a great suggestion for the very reason mentioned. All the symptoms talked about are common and the bottom line is there is very little you can do about them until they pass. NSAIDs for pain/inflammation. Lots of rest, shower several times a day. Always made me feel better. I used the nausea and anorexia as tools to loose weight. I would suggest very minimal exorcise daily. I walked to the mailbox. It will help restore your energy levels and other systems in your body that have been affected. Increase only in small increments. Drink lots of water and Gatorade or Propel.

[Reply](#)

Thanks for your comment. I read all comments and do my best to respond to questions, usually in a new post.

If you have adrenal issues and want to connect with other patients the following message boards are wonderful resources:

<http://www.mdjunction.com/forums/adrenal-insufficiency-discussions/general-support>

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

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