Coping When Lupus Impacts Your Appearance

by ANNA SCANLON

Feeling Beautiful Despite Lupus

The funny thing about lupus, or at least one of the most ironic things, is that when you are the sickest, your skin can glow and make you look as though you've just come back from a vacation somewhere tropical. This will, of course, prompt the "But you don't look sick!" comments, even though you feel like you're about to drop dead.

For many people with lupus, their skin looks amazing during a flare, which is something of a blessing and curse.

Although glowing just-got-back-from-Hawaii skin is one side effect of the illness, there are many more symptoms that make you look, and feel, less than your best. These side effects of both lupus itself and the medication used to treat it can shake your identity to the core, especially for women, who are taught to take extreme pride in their appearance.

Visible symptoms can range from facial redness and rashes to significant weight gain and partial or total hair loss. While these are terrible for anyone, for a woman, these physical side effects can be especially devastating.

Luckily for me, I haven't experienced many physical changes when it comes to lupus — believe me, I recognize how deeply fortunate I am.

The only real drama I had was when I was a bridesmaid in a wedding for a high school friend. My dress was a strapless gown and, of course, before the big day a lupus rash appeared on my bicep for the entire congregation to see.

Thankfully, my friend wasn't a bridezilla and didn't think it was cause for concern, but unfortunately for me, it was on the side that faced the crowd during the ceremony. Not particularly cute, and although I would imagine everyone was too focused on the bride and groom to notice my rash, it still played on my mind.

Butterfly Rash

I also experience facial redness here and there, especially in the form of a butterfly rash across my nose and cheeks. Though the technical name for this is malar rash, it is called a 'butterfly' rash because of how its shape resembles the beautiful insect — but a red, raised rash across your face isn't exactly majestic.

For some people, this symptom can be extremely noticeable, and very difficult to cover up with make-up that isn't specially made for scars or tattoos. There are theatrical foundations designed to cover these things on actors, and for a special occasion you could use a product like this to cover up a particularly bad butterfly rash. I wouldn't, however, recommend it on a daily basis.

This sort of make-up can be purchased from theatrical supply stores or online, but it is important that you speak with both your doctor and a make-up artist before slapping it on your face. Depending on your rash, it may do

more harm than good. But it may also help in allowing you to enjoy a special occasion and appearing rash-free and more confident for a few hours.

My butterfly rash tends to be very mild, so I am able to cover up the redness with a little extra make-up. In order to neutralize my screen, I wear a color correction green primer, which is applied before any other make-up.

Green counteracts redness, which helps neutralize your skin tone. After that, I place some concealer on my nose and blend it out followed by foundation to set it. I set it all with a powder.

This formula has seemed to work wonders for me, as before I did this, I often found myself getting home after being out all day with a Rudolph nose. If your malar rash is slight, the redness on your cheeks can work as a benefit, and you can either skip blush altogether or simply apply a small amount of tint to keep your cheeks looking rosy.

Next page: Coping with weight gain and hair loss.

Weight Gain

Lupus weight gain is a common side effect of the condition and medications used to treat it. I experienced some weight gain when I was on steroids, which can totally mess with your self-esteem.

Although my weight gain was only slight because the course of steroids was only over a month, for some, it can be significant if the medication is taken over a long period of time.

I have heard doctors say that steroids don’t actually cause weight gain, rather they cause an increase in appetite. Some claim that weight gain can be avoided altogether if you keep a close watch on your food intake, but I’m not sure this is the case.

For many, steroids cause fluid retention in the face and jaw that give way to a “moon face” or “chipmunk cheeks.” Even the thinnest of people will experience this type of facial bloat on long-term steroids, which can make you totally self-conscious.

When I was on steroids, I am unsure if my appetite was increased or if the medicine simply made me retain weight, but the cravings on steroids are almost unbearable. I tried to monitor my calorie intake, but it didn’t seem to do much good.

Besides taking a physical toll on your appearance, steroids can make you feel extremely energetic, give you terrible migraines or give you a weird metallic taste in your mouth. Although your doctor may tell you how to cope with steroids or what to expect, they aren’t counselors and often won’t tell you how to deal with the changes to your physical appearance.

This is where it is extremely important to join a support group for those with lupus or lupus-like diseases. Together with other lupies, you can discuss your vulnerability, the changes in your appearance and strategize ways to minimize or eliminate weight gain associated with steroids.

Weight gain or inability to lose weight can also play a role in your life with lupus even without steroids. For many people, lupus makes them totally lethargic when they are in periods of flare.

Although I enjoy exercise, if I’m not feeling well, it can be difficult to even get out of bed. Couple that with not being able to cook for yourself and voila, you have a recipe for gaining weight, or at least being unable to lose weight.

For me, this takes a huge hit on my self-esteem, as I have always had body image issues, and in the last year whilst being ill I have packed on 20 pounds or so. I have managed to lose about 12 of them, but there are a few

that won’t budge, and I’m not too happy about it.

Still, when you’re in bed all day, there is little you can do to curb it besides simply cutting down on your food intake, which doesn’t even always work when you aren’t kickstarting your metabolism with regular exercise.

Hair Loss

Although I have never experienced this myself, lupus can also cause women to lose their hair, which is arguably the most devastating symptom. Some women may experience a significant hair thinning, while others may lose their hair altogether.

Again, this is when going to a support group to help cope with such a monumental physical loss is key.

For some women, wigs or extensions can help temporarily “fix” lupus hair loss, but it is simply a band aid instead of a full fix. For most women, their hair comes back after their medication is discontinued or their lupus flare passes, but it doesn’t make it any less traumatic when it is occurring.

It is important for all women to feel beautiful, but when suffering from lupus SLE, it is especially important to find ways to bolster your self-esteem and keep you feeling mentally well. After all, feeling mentally well and positive is a great way to kickstart your body and helping it physically recover.