Living With Lupus Skin Rashes

by BARBARA LEECH

Living With the Skin We're In

Lupus warriors Elena Anciro and Barbara Leech discuss their experiences with lupus skin rashes.

Barbara's Experience

When I was a teen I had horrible skin; skin that was mottled with acne and brought me such ridicule and shame that I usually came home from school and wept. Now as an adult, lupus rashes stir those same feelings of self-doubt and shame.

The malar or "butterfly" rash on the face is one of the most widely recognized symptoms of lupus. It is red and slightly raised and looks like an allergic reaction. Some people with lupus do not experience this rash, and thankfully it only happens to me when I am in a full-blown flare.

When it does come, I am horrified by my reflection in the mirror. It is hard to hide, even with the best makeup, and it brings on questions from people.

It typically goes something like this: someone asks about the rash, and I tell them that it's lupus. They proceed to ask me what lupus actually is. I get exasperated having to explain the disease, and they act as though it's contagious. I briefly explain that I'm not a leper, and find myself fed-up again.

People living with lupus deal with other skin issues as well like lupus bruising. I've experienced discoid rashes on my arms and legs, painful and expensive biopsies to determine whether or not lupus caused them, as well as sores in my nose and mouth. All are very common skin issues with this disease and leave you feeling like the lupus is eating you alive.

Elena's Story

When I was told that my particular kind of lupus could potentially affect my organs, my skin had not entered my mind. In fact, I thought of every other vital organ except my largest one.

It's easy to forget that our skin is our bodyguard, protecting our internal systems from environmental attack. It is our waterproof (yet selectively absorbent), regenerative messenger to our nervous system.

According to the Lupus Research Alliance, four out of 10 official criteria for systemic lupus are skin-related: Malar rash, discoid rash, sensitivity to sunlight, and oral ulcerations.

Looking back, my lupus symptoms started with my skin, but at the time I wasn't aware that it was connected to a larger condition. I had large hives on the back of my legs, as well as a malar rash, which has been the most consistent of my symptoms, even in times of low lupus activity.

In my case, I ignored my rashes because I didn't have the right information, which could have provided insights into my lupus activity and treatment.

Understanding and Coping With Lupus Rash

There are four main types of rashes that can occur and they play an important role in establishing a lupus diagnosis. It is also important to have a keen, general awareness of your skin health since 60-70 percent of people with lupus report some kind of skin problem.

Acute Cutaneous Lupus Erythematosus (Malar/Butterfly Rash)

Malar comes from the latin root word "mala," which means cheekbone. Malar rash most often occurs over the cheekbones and the bridge of the nose in a butterfly shape, hence it's other name, butterfly rash.

Butterfly rash is seen as a typical lupus symptom, occurring in 40 percent of patients. The butterfly shape of this rash is also the symbol that is most used by lupus organizations and awareness campaigns.

According to Lupus UK, "it can appear as a blotchy pattern or completely red over the affected area, and can be flat or raised. The rash can be mild or severe but is not usually painful. It can be itchy if it is more like a rash than a blush and some patients even report a 'hot' feeling with more severe malar rashes."

Butterfly rash can be triggered or worsened by UV rays from the sun or fluorescent lights. Fortunately, this kind of rash can resolve without scarring.

Subacute Cutaneous Lupus Lesions

There are two types of subacute cutaneous lesions, both of which are photosensitive.

Molly's Fund describes the first type as red pimples initially, developing into psoriasis-like lesion with red, scaly patches that occur on the arms, shoulders, neck, trunk, and less so on the face.

The second type is a flat lesion, which expands outward as a red-shaped lesion with some scale on the edges. The inner centers of these lesions gradually fade, creating red circles with lightened insides.

Appearing on the face, neck, chest, arms, and back, these lesions usually heal without scarring. However, in some cases, a non-depressed scar or area of de-pigmentation is left in place of the lesion.

Chronic Cutaneous Lupus (Discoid Lupus Rash)

According to Lupus UK, discoid lupus is only found in approximately 20 percent of SLE patients, but it also occurs in people with no trace of systemic lupus. Their lupus is only skin-related.

Only one in 10 people with skin-related discoid lupus will develop the systemic form of the disease.

Red, scaly, and thick, these lesions occur most often on the scalp and face, but can also appear on other parts of the body. The lesions are usually pain and itch-free, but scalp lesions can cause hair loss that could become permanent if those lesions scar when healed.

Discoid lesions are photosensitive and can result in scarring and discoloration. Long-standing lesions are at risk of developing cancer, so it is important to monitor skin changes and consult a dermatologist.

The singer Seal is an example of a famous singer with discoid lupus. His scars are what remain of his facial lesions.

Bullous Lupus Erythematosus

This type of rash is arguably the most photosensitive. Bullous rash manifests as fluid-filled blisters on areas of the skin directly exposed to sunlight.

Hives/Welts

Both hives/welts and bullous rash are outside of the four main types of lupus rashes, but are still known to occur in lupus patients.

Next page: What treatments are available for lupus rashes?

Treatment for Lupus Skin Rash

Add a dermatologist to your healthcare team and ensure that you consult them when you notice any skin changes.

The appearance of rashes can cause self-consciousness, stress, and anxiety. Topical steroidal creams can help reduce inflammation, as well as more natural treatments like aloe vera, oatmeal baths, vitamin E oil, etc.

Most people with lupus are already taking either an anti-inflammatory or anti-malarial drug as treatment, which are effective in treating lupus rash. Molly's Fund recommends disease modifying anti-rheumatic drugs (DMARDs) and immunosuppressive drugs for severe malar rash, which treats the disease and also prevents recurrence.

Avoid the Sun

Since photosensitivity plays such a large role in almost all types of lupus rashes, it is important to limit exposure to UV and artificial light.

Applying sunscreen that has an SPF degree of 30 or higher is important to adequate prevention, along with the amount of times you reapply. If you are out in the sun for a length of time, it is important to reapply sunscreen every two hours. This is to ensure that you are getting the most out of your sunscreen.

Avoiding any type of direct sunlight is also important, and this can be done by wearing large hats and tight woven clothes. While these suggestions are not guaranteed to stop the potential flare of cutaneous lupus, they have been shown to be highly effective in reducing the chance of a flare.

Topical Creams and Ointments

While medication will require a doctor's prescription and might not be available right at the moment you need it, there are some other options on how to soothe the itch. These options include using ointments like corticosteroid cream that will most likely help to reduce the itch. This cream should be applied directly to the portion of the body that is experiencing the outbreak to help reduce the itch.

Committing to general skin health is one of the best things that you can do in regard to rash prevention and care. Remember, our skin is our largest organ and deserves our attention!

The last thing we want to do is irritate the skin further when it is already dealing with a lesion or malar rash. Here are some suggestions on how you can invest in your skin health:

- Drink plenty of fluids every day, especially water
- Avoid or reduce dehydrating fluids like coffee and alcohol
- Avoid smoking
- Invest in toxin-free, mild soaps
- Consider toxin-free, SPF make-up
- Moisturize often with a moisturizer that contains SPF

- Use sunscreen daily and avoid tanning salons
- Limit bath/shower time, which can dry out your skin
- Use a humidifier every night
- Steer clear of scented products
- Avoid using fabric softeners that irritate the skin

Work With Your Doctor

If none of these options seem to be viable ones for your particular flare, it is a good idea to contact your doctor to discuss other options you might have when it comes to lupus flares. It is important to explain to your doctor what these flares include, how often you experience them, and the types of treatments you have already tried.

While some immunosuppressive medication might work for some patients who experience cutaneous lupus flares, they might not work for you, and that is okay. Different medications have the potential to affect each patient differently. Working with your doctor to find the right course of treatment for your cutaneous lupus is an important step in learning how to control and treat it.

Lupus is often invisible, but when it is not, is can be devastating to our self-image and our self-esteem. Remember that it is the inside that matters most.

Take Care Of Your Skin And Your Emotional/Mental Well-being

Lupus is most often an invisible disease, because a person with lupus may not look sick at all. For those who suffer from a lupus rash, this is not the case.

Each lupus symptom creates both physical and mental challenges. Simply seeing photos of lupus rash can cause fear and anxiety.

Dealing with changes in appearance can add to the immense stress of dealing with other physical symptoms. It is important to share your feelings with a close friend or a counseling professional.

Skin involvement happens to most people with lupus, so access online support groups and find out their tips and tricks — you don’t have to go through this alone.