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How to live with sun sensitivity by Mary Dixon Lebeau

Like most people, Laurie Boswell has a routine each morning before leaving her house and going to work. But Boswell's routine includes more than the typical face scrub, cup of coffee, and tooth-brushing. Before she goes out, Boswell, 47, also has to prepare herself for the light -- both sunlight and artificial -- that she'll face during the day.

As many people with lupus know, the road to diagnosis can be long. For Boswell, the sun shed light on the problem.

When Boswell moved from Florida to the West Coast, she immediately noticed she reacted more strongly to the sun. "If I was out in the sun for too long, I would get an itchy rash," says Boswell, a senior administrative clerk. "I just assumed the UV rays were stronger on the West Coast than on the East Coast." In the summer of 2006, Boswell developed a cutaneous lupus rash. "I had an all-over rash that did not look like hives. At first it started in just one small area and was diagnosed as fungal. After it spread all over and was biopsied, it was diagnosed as cutaneous lupus," she says.

Photosensitivity -- abnormal sensitivity to light -- is common in people with cutaneous lupus. Often, the sensitivity causes skin lesions, rashes or sores, fatigue, and joint pain. And often, going indoors doesn't provide relief. To understand why, it may help to understand the basics of UV lighting -- better known as ultraviolet rays.

You're Not Being Oversensitive

The sun radiates a variety of rays, most notably ultraviolet A (UVA) and ultraviolet B (UVB) rays. UVA rays are equally intense throughout the day and the year, while UVB rays are significantly stronger in summer, especially between 10 a.m. and 4 p.m. Unfortunately, those with lupus can be sensitive to both UVA and UVB rays, though many find relief by avoiding direct sunlight between 10 a.m. and 4 p.m. This same sensitivity can extend to indoor fluorescent light.

"My lupus patients always want to know why they must avoid significant sun exposure. Why am I spoiling their fun?" says Thomas J.A. Lehman, M.D., chief of the Division of Pediatric Rheumatology at Cornell University's Sanford Weill Medical Center.

"The truth is that the sun -- any source of ultraviolet light -- damages our skin. These high-energy light rays penetrate into skin and damage the superficial cells," Lehman says.

Now living in Nevada, Boswell recently experienced this firsthand -- this time indoors. In February 2008, she had a flare that started with hives and a low-grade fever. She felt extremely worn out, especially after being at work. It turned out to be related to her workplace environment.

"I sit in a cubicle that is surrounded by fluorescent lights," Boswell explains. "I noticed I was itching whenever the lights were shining on my body."

Boswell asked her employer for disability accommodations based on her photosensitivity, and the company agreed.

“They’re accommodating my needs by purchasing the necessary UV light filters to go over the fluorescent lights in my work area and office,” she says. “They’ve also turned off the fluorescent lights above my head and changed the type of bulbs in the light fixtures facing me.

“With those changes, I feel much better,” she says.

With the arrival of warmer weather, people with both cutaneous lupus and systemic lupus who are light-sensitive are made even more aware of their reaction to sunlight. The summer sunshine can be tempting, and everywhere you look you’ll see people out and about. But, like Boswell, many people with lupus find that any exposure affects them adversely.

“Now I prepare to go outside in the sun by putting on sunblock all over,” says Boswell. “I use a special facial sunblock of at least 30 SPF, then I spray another sunblock all over my hands, back, and other areas I can’t reach with the lotion.”

Fashion With Flair—and Function

Fortunately, the fashion world has responded to the need for sun protection—and that means stylish protective clothing that allows those with lupus to cover up fashionably. Retailers sell sun-protective clothing, swimwear, sunglasses, and hats that offer protection for enjoying the great outdoors. Men, women, and children can find attractively designed clothes that fit almost every occasion—and will allow them to enjoy the outdoor activities they love.

Commercial artist Shirley Niro, 61, has always enjoyed dressing well—something that used to prove difficult while dealing with her light sensitivity.

“I have difficulty getting the proper sun protection while staying stylish,” says Niro, the owner of Prints Charming in Milford, MA. “I need the protection, but I don’t want to make anything obvious. I’m pretty vain and I don’t want to draw attention to my lupus,” she admits.

Niro says she has always been sensitive to light, both indoors and out. “Long before I knew what was wrong, I could never go in the sun, and I could never shop in Wal-Mart because of the UV lighting,” she says. Eleven years ago, she was diagnosed with subacute cutaneous lupus erythematosus.

“All the research I’ve done says indoor lighting has minimal UV rays, and on the General Electric Web site, they claim that being under UV light for the hours of a working day shouldn’t affect people,” Niro says. But her own experience proved otherwise.

“[Indoor UV lighting] does affect me terribly,” Niro says. Her freelance graphics design work often took her to a variety of work sites—each with different lighting setups. “If I have to work on a site with fluorescent light two days in a row, the cumulative effect can be unbearable,” she says.

Niro took to wearing hats whenever she worked at locations other than her home. She requested filters for the lights, but says the request wasn’t honored because, as a freelancer, she wasn’t a regular employee of any of the companies where she had assignments.

Niro finally decided to shed the hat—and open her own studio, where customers could see her in an atmosphere that protected her from UV rays. “Now I have the most wonderful space with a UV-protective skylight,” Niro says. “It’s full of light, but nothing that can hurt me. I have UV-protective shields on everything, but no one would know. The studio is absolutely beautiful.”

For those without the luxury of their own studios, well-designed hats such as those sold by retailers like Coolibar, SunGrubbies, and Sunday Afternoons can reduce exposure to light, thanks to their wide brims and the high

ultraviolet protection factor (UPF) rating of the materials used in their construction. A hat made of fabric with a UPF of 50 or more and a brim of 4 inches allows maximum protection.

Sun-protective clothing is sold on the Web by the above-mentioned retailers, as well as SunPrecautions and TripleJSportswear. Men can purchase such staples as hoodies, long-sleeved cotton T-shirts, golf slacks and shirts, and basic button-down dress shirts. Women will find everything from skirts and blouses to yoga pants and spa robes; some retailers offer plus-size clothes as well. Children can find a variety of shorts, shirts, and even swimsuits that offer additional protection from the sun's rays.

Those with lupus also can give their favorite clothes extra UV protection by using RIT Sun Guard Laundry Treatment UV Protectant, which is recommended by the Skin Cancer Foundation for people with skin cancer. Be aware, however, that the additive, which is added to the wash cycle, only boosts the UV protection—and then only temporarily. For example, a T-shirt, which usually has a UPF of 5, will increase to UPF 30 after being washed in the treatment. The treatment is good for 20 additional washings, so it's important to keep track of when it was used and, of course, to continue to wear sunscreen. Furthermore, sunscreen should be used all over your body, even when wearing protective clothing.

You should also have your optician apply UV-protective coatings to sunglasses and eyeglasses to help sensitive eyes avoid painful rays. Treated umbrellas will offer extra protection from the sun—and the additional bonus of keeping you cooler.

“The important thing is to plan ahead,” advises Niro. “It's the only way to do what you want to do. I always carry an extra sun hat and sunblock lotion in my glove compartment. I don't want illness to interrupt my life, so I do everything in my power to prevent that.”

Don't Be in the Dark

Also remember that overcast days and shady areas may seem safer than bright sunlight if you're sun-sensitive, but clouds and shade do not provide protection from UV rays. When indoor protection is necessary, remember to use sunscreen inside and install filters on lighting fixtures and light shields on windows.

“I always liked being outside, and now I have to dress for the occasion and put on my battle gear—sunblock and protective clothes,” says Boswell, who also says she stays indoors as much as possible between 10 a.m. and 4 p.m. “My sensitivity does limit my recreational and family activities, and I now do most of my shopping on the Web.”

People who share Boswell's sensitivity should listen to their instincts and consult with the LFA if they need additional information or assistance in getting UV-protective products or accommodations. “Enjoy limited outdoor activity, and rest as much as possible,” says Boswell. That way, you can have your moment in the sun—without paying for it later.

Protect Yourself from UV radiation:

There are four ways to protect yourself from UV radiation: Absorb it, avoid it, block it, or reflect it. Sun-protective fabrics differ from typical summer fabrics in several ways: They have tighter weaves, are made from synthetic fibers, and are produced in darker colors. The fabric blocks, the color absorbs or reflects the light, and the chemical additives absorb UV radiation. Are these clothes worth the extra cost? Just ask anyone with sun sensitivity, including those with lupus, and the answer is a resounding YES!—Andrew G. Franks Jr., M.D., F.A.C.P., dermatologist and rheumatologist at New York University Medical Center

Medicine And The Sun

People with lupus need to be aware that the medications they take may increase sensitivity to the sun, leading to skin rashes or a lupus flare. The classes of drugs that have been implicated in causing increased photosensitivity include:

- sulfonamides (antibacterials used to treat infections)
- tetracycline (antibiotic used to treat infections)
- fluoroquinolones (broad-spectrum antibiotics)
- thiazides (diuretics)
- phenothiazines (tranquilizer and pain medications)
- tacrolimus (for preventing organ transplant rejection)

Talk to your pharmacist or doctor to learn more about side effects of the medications you are taking.

Sun Protection Resources

Coolibar www.coolibar.com – 800-926-6509

RIT Sun Guard Laundry Treatment UV Protectant – www.sunguardsunprotection.com – 866-871-3157

Sunday Afternoons www.SundayAfternoons.com – 888-874-2642

SunGrubbies www.sungrubbies.com – 888-970-1600

SunPrecautions www.sunprecautions.com – 800-882-7860

TripleJSportswear www.triplejsportswear.com – 800-555-5142