Getting Through Winter With Lupus

by BARBARA LEECH

Coping With Lupus and Cold Weather

The holidays are over and what follows is often difficult for someone with lupus to endure, especially if you live in an area that experiences freezing winter weather. Stretched out before us are weeks of bitter cold temperatures, blustery wind and snow. And the wolf is very temperature sensitive.

With lupus, the accompanying Raynaud’s Syndrome, and a recent diagnosis of Hashimoto's thyroiditis (another autoimmune disease that attacks the thyroid and makes one intolerant to cold), freezing temperatures can cause me more pain than I can bear. My body seems to require a steady year-round temperature between 64-78 degrees and not too sunny.

But I live in Maine, where that temperature range is short-lived, showing up for only a couple of weeks in June.

How the Cold Impacts Lupies

The temperature in recent weeks has been below zero, and with lupus that means days and nights where my body is in constant pain. From my joints feeling like they were struck with a hammer, to my skin numb and burning like I am sitting naked in the snow, the temperature outside has a substantial influence on what I can do each day.

I'm not sure if others have the same volume of cold temperature-induced flares as I do, but I know that as much as I appreciate the beauty of winter, the freezing temperatures are my enemy. I hate it, and I hate my body for ruining a perfectly good season and all the activities that it offers.

There are many factors that cause someone with lupus to react badly to the cold:

Raynaud’s Syndrome

Raynaud's syndrome causes fingers, toes and parts of the face to turn purple or ghost-white (depending on the amount of blood-flow cut off) and burn like they are on fire. Essentially, the cold triggers blood vessels to clamp off blood flow to these extremities.

Raynaud’s can range from mild (finger tips turn white/blue and numb if exposed to cold, but quickly return to normal when warmed) to severe, where the skin tissues on the toes and fingers can actually start to break down and form sores from the lack of adequate fueling from blood flow.

Mine is so severe that it seems to have moved into my limbs, so my legs and arms will also appear purple when I am cold. The only way I can describe the pain is to say it is like cold, icy, burning nerves.

Someone without lupus can only begin to relate if they go outside on a snowy, very cold day and stick their hands in a snowbank, keeping them there for say, 10-15 minutes. That is the cold burn lupies feel on a daily basis,

wearing gloves and simply walking to their car.

Aches and Pains

Lupus causes joints to swell and burn in the cold too, and I seem to feel the cold so much more deeply than I used to. Once I become cold, I don't feel like I can warm up again for hours.

I also notice that I tense up my entire body to brace against the cold — I can't stop myself — and this causes muscle aches in my back and neck for several days that follow.

Skin Rashes/Sores

The blistery butterfly rash is back and I swear it always makes an appearance after I'm subjected to the icy winds of winter. The cold will make my rash burn, so my face actually hurts for several days after it appears.

Sores inside my nose appear more often and last longer during the cold months as well. I don't know if it is due to cold air triggering a slightly runny nose or if it is just a typical reaction to the cold. My nose has been sore since November.

Coping Strategies

I have developed a few coping strategies that get me through the winter with less discomfort. Planning is key and extra care is a requirement:

- **Invest in a small space heater:** I work from home, so I do have control over the thermostat (huge blessing) but I can't afford to keep the house as toasty as lupus requires. I have found that running a small electric space heater, which I place at my feet while I work, can make all the difference to my comfort level.

- **Dress in layers.** Body heat gets trapped in your clothing easier with more layers to buffer its escape.
- **Drink something warm:** From my morning coffee to my afternoon tea, I rely on a warm beverage at my desk every few hours.
- **Stay hydrated.** Weird tip, but I find that if I am well hydrated, I tend to not feel as cold. Perhaps it helps the blood flow, but water is important even in cold weather.
- **Always have extra clothes/blankets handy:** I keep extra supplies of warm clothing with me in my car. Nothing is worse than getting to someone's house or out shopping and realizing I am still not dressed warmly enough to make it through the next few hours. Extra sweatshirts, gloves, a pretty scarf and a fleece throw-blanket are always in the back of my car in what I have called my winter survival kit.
- **Use warming inserts for shoes:** Basically you cut them to fit inside your shoes/boots and they work to insulate against the cold, keeping the bottom of your feet warmer.
- **Use chemical warming packs in pockets:** They sell them in home improvement stores and in the camping/outdoor section of department stores. Basically you activate them and they produce heat for several hours. Perfect for inside gloves or pockets to warm up those Raynaud's affected fingers.
- **Eat small snacks:** After you have eaten, you have more fuel in you to maintain your body temperature.
- **Skip the alcohol:** This may make you care less about being cold, but it actually thins your blood and your body will feel the effects of cold temperatures easier.

What have you found works best for keeping warm during harsh winters?