Your Guide to Living With Lupus in the Summer

by BARBARA LEECH

Lupus in the Summer 101

Summer is supposed to be more carefree than the winter months, right? Many of us think of it in a special way, and probably have done so since grade school, anxiously awaiting its arrival and the warm beautiful freedom it brings.

I have spent the past six months waiting for it, bundled up to protect myself from the harsh winter we had where I live in Maine (which felt more like Alaska this year) and I am excited for summer.

But lupus in summer can be equally as challenging lupus in winter can be. It just presents different challenges to overcome and strategize for. I am up for a change of pace, mainly because I thought winter would never end, but I know that a hot summer is not going to be as carefree as I remember it as a child.

From physical reactions to the sun, to issues with the heat AND air conditioned air, to even the shoes I pull out of the closet, summer is one more thing those of us with lupus must navigate carefully to survive.

As a mom, I have to have some sort of action plan to keep up with what I must do this summer and try to be present for my children as they enjoy their summer off from school. I have created some strategies for making the most of summer and avoiding extra pain or flares.

Here are few of the areas of concern I focus on, and what I do to deal with them.

Summer Shoes

That’s right, even my footwear can be an instigator for lupus pain. I have to have just the right flip flops or my summer will be a total flop. Since lupus, I no longer can wear those beautiful strappy sandals or high heels because of lupus foot pain. My feet require support in the right places and nothing too tight. There needs to be some arch support, but too much will cause foot pain.

Shoe shopping used to be fun but lupus has changed it into a ridiculous game of “what shoe will be least likely to hurt me?” I tend to do better with pretty simple flip flops that have some arch support and firmness to them, not made of foam, and that have small to medium straps. Anything that varies from that seems to cause pain in my feet that could rival a broken bone.

Running/walking shoes are even trickier because what feels OK in the store may hurt me over the course of wearing them for the day. I look for sneakers that don't rub the back of the ankle and have adequate arch support, but are not overly raised in the arch area. Lighter weight shoes do better than those with any weight to them.

As much as I love high-heeled wedge sandals, I stay clear of them. My closet, once a shrine to my shoe fetish, now displays a pretty bland collection.

Sunshine

I used to love the sun. I guess I still do, but I am not allowed to enjoy it like I once did. Too much direct sun exposure can cause a lupus rash, swelling in my skin like an allergic reaction, blisters and even make me physically ill, with stroke-like symptoms.

Once on a summer vacation and thought I was actually having a mild stroke. Too much sun one beautiful day and I suddenly could not walk straight, I felt weak, lightheaded, confused and it was difficult to talk and form the words I was thinking.

Doctors ruled out stroke, did tests for multiple sclerosis and finally determined that the white lesions on my brain were caused by lupus and that they react to extreme heat and sunshine. Much like with MS, if the heat from the sun gets the better of me, it temporarily interrupts the signals in my brain and causes these stroke-like symptoms.

Because of this, I have to avoid getting too much sun and overheating, which happens quickly on a hot sunny day. I plan my outings and seek shade. I wear sunscreen (SPF50) and use hats to shield my head and face from direct rays. I also have some SPF clothing that helps protect my skin.

If I am heading out for a day in the city with my boys, I plan stops that have access to AC; a bakery shop for a cookie break or a stop to browse in the toy store and cool down. We picnic in a park that is near the harbor, so there is a cool breeze and plenty of trees for me to seek shelter from the sun.

For baseball games, I pack frozen icepacks (the soft gel-like kind typically designed for injuries) to place on my neck or wrists to cool down my body. A spray bottle that spritzes out water is also helpful to keep me going on hot, sunny days.

Food

Summer is a time where we are tempted to eat more processed foods, chug down ice cold soda, and forget that these items can be big lupus triggers.

A hot dog with nitrates will send me into a flare within hours of eating it and soda is a chemical storm for my lupus symptoms. I used to cheat and drink it only on special dinners out (some foods just cry out for soda!) but after suffering the repercussions each time, it became undeniable that soda was the cause of a lot of suffering.

So I have changed how I eat during the summer. I've found companies like Applegate Farms and Al Fresco produce really great hot dogs, bacon and sausage that is nitrate free. I avoid regular potato chips and instead choose organic sweet potato chips – some have chia seeds which is great for lupus inflammation.

For quenching my thirst, I stick mostly to water with lemon or iced green tea. Summer is a great time for fresh fruit and veggies so I try and focus on fresh grown produce that will fuel my health, not foods that will trigger a lupus flare up.

If you are like me, you are both excited and trepidatious about the coming summer months. I hope for enjoyable time with family and soaking up weather that does not involve snow, but I am aware that without proper planning and precautions, summer can wake the wolf and make me miserable. Always plan ahead and avoid the things you know will trigger pain or a flare.