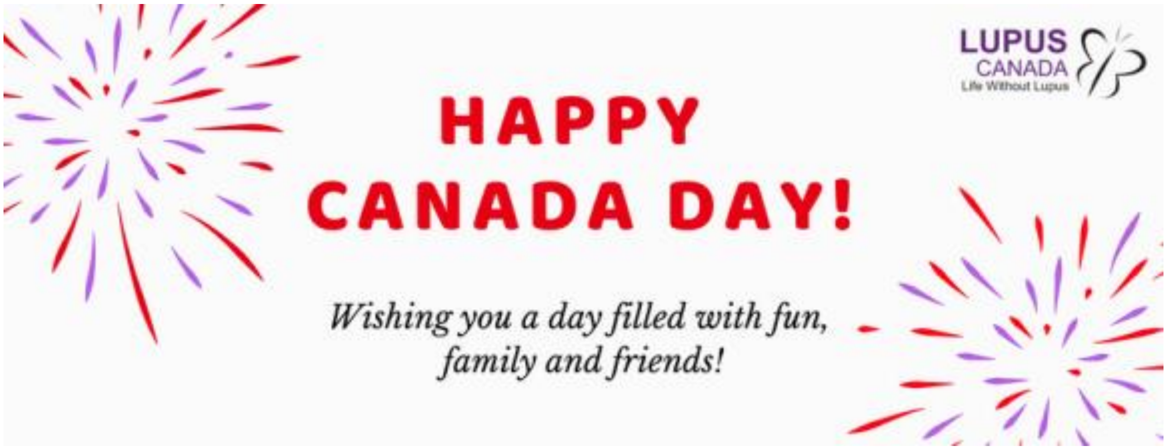
Let's Talk Lupus

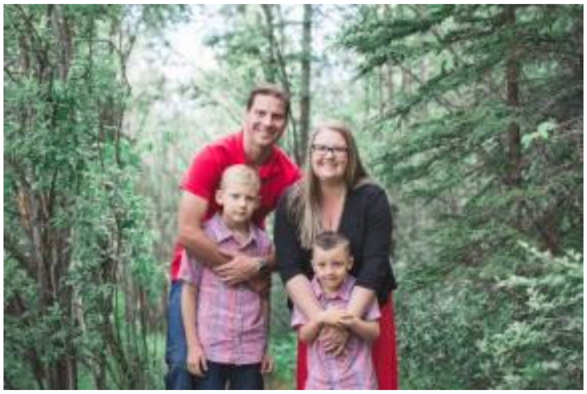
Monthly E-Newsletter

On July 1st, we celebrated Canada Day! This holiday is a reminder to all Canadians of the amazing privilege we have to live in such a great nation, and also an opportunity to see some festive fireworks - Happy Canada Day! Also at the end of this month, we will celebrate International Day of Friendship. For many lupus patients, friends make up a huge part of support systems and often, are the people who we can turn to when having a hard time. Happy International Day of Friendship – we appreciate you!

In this month’s newsletter, we will be sharing some information on travelling with lupus. Travelling is already stressful, but add lupus into the mix, and there are many more things to consider and prepare for. Especially if you are going somewhere where the weather is drastically different from what you are used to, this can induce a flare in your symptoms. Take a look at this month’s article "5 Tips for Summer Travel" to get some insight on how to better ready yourself for vacation and have a great time!



My Lupus Story by Andrea Pinter



Living with an invisible illness.

I had started writing this in my head, while waiting in line at the grocery store (where I tend to spend a lot of time). I was thinking, "when they ask me how I am, do I give the politically correct answer and say "good, thank you, how are you?" Or should I give the actual answer?"

I try not to complain because I don't want to run out of friends or family, or sympathy and support. Especially because this could, and might, get worse.

Every day is a struggle; it's a mental game. My joints hurt every single day - it sometimes takes an hour or more to walk normally again. Just going to get my coffee in the morning hurts.

My skin is always fighting me: currently both of my ears are infected from the psoriasis & scratching (as well as 2 patches on the inside corners of my eyes), and It takes me about an hour to shower and put all my lotions on, which explains why I hardly ever do my hair.

Often I'm also fighting canker sores. I love food, it's part of the reason I became a chef. Canker sores take a lot of the joy out of the eating and tasting of my meals.

My immune system is weaker than a newborn baby. I'm currently on 3 immune suppressing medications. I'm working in an elementary school, so I'm always on high alert with those germ filled kids.

Last December, a common bacteria found on all of our skin got beneath mine, and my face blew up like a balloon! I had to be on IV antibiotics for a week, and I can expect this type of thing to probably happen again.

I almost constantly have a low grade fever, and run really hot. Never minding the fact that I've put on some extra "insulation" over the past few years. I feel bad for Jon, because I need the window open basically all year round just to sleep comfortably.

Blood tests are something that I need to do regularly. I'm actually pretty lucky that it's only once a month right now.

Being outside in the summer has been my most favorite activity for the past 36 years.

Now, I break out into a rash if I’m in the sun, and/or burn very, very easily. My risk for skin cancer has increased, which totally takes the fun of it out. My doctors recommended spf clothes, but I personally think I’m still too young and cute for that "style". Those that know me well, know I, like my father, don’t like the feeling of grease on my hands........ thank goodness for spray sun screen

This winter, I learned I’ve also developed mild reynauds syndrome. That’s when the circulation to your fingertips and toes slows down/stops when they are cold. I live in Alberta, need a I say more?

Brain Fog....... Honestly, I’m not sure if this is real? Maybe it’s a combination of getting older, trying to balance being a mother/wife with 4 jobs and 2 volunteer positions

Either way I can’t keep thoughts for very long unless I write it down. Even then, I have to try and remember where I wrote it.

Depression is a battle I fight day in and day out. In 2006 I hit an absolute rock bottom and had a suicide attempt. Every day since then I have tried my hardest to make my life better, and happier. Ive been on antidepressants since that day, with the exception of coming off for both pregnancies. I recently tried to come off/down in my dose, and it didn’t go so well. The suicidal thoughts returned, and I recognized what was happening and got help. Plus, It’s hard not to be depressed when you’re in constant pain, knowing your immune system is trying to battle its own body.

Fatigue is honestly my biggest complaint. I use to be able to work 18 hour days in a hot kitchen without a break. I worked one full time job, and a part time job, all while going to school full time. Now if I hit 10,000 steps, I can hardly make it to 8:30 before I need to go to bed. I can sleep anywhere!

I have been so fortunate to have been born into a family that loves me unconditionally.

I don’t need to tell them my daily struggles, they just know. Both my sisters can tell when I need them the most, they both will drop everything to be my supports. (Including proof reading this) Even when their lives are full to the brim too. My mom and dad are always there to help me with my kids (including my big kid). When I’m sick they step up and come to my rescue - drive me to the hospital, stay with the kids, make us dinner, basically anything I ask. When I’m healthy, and want to take advantage of the good feeling and spend time with my friends, they accommodate that too. My husband and best friend - he lets me cry when I need to, but never alone. I’m really taking the "in sickness and in health" part of our wedding vows for a run. He works incredibly hard to provide for the kids and I. He picks up the house hold slack when I’m unable to. Never minding always having a job with medical coverage to help pay for all my medications.

Both of my children are incredible young men too. They are growing up so fast and are learning to help out around the house more, to take some of the load off of me. They both understand how much I hate messes, and tend to both be pretty tidy. The friends that I’ve made along the way, in the past 36 years, have made it easier too. They will also give me the support I need when I need it. Allowing me to vent, cry, laugh and just be me. I’ve learned to cherish the ones that enrich my life, and who are there whenever I need them, not just when it’s convenient.

I guess in all, the cashier at save-on doesn’t want to hear all that, but it sure feels good to tell you.

What's your lupus story? We'd love to hear it. Send us your thoughts and experiences to be featured in Lupus Canada's national monthly e-newsletter. Email your stories to leanne.mielczarek@lupuscanada.org

Lupus and Sun Exposure

Source: *https://www.healthline.com/health/lupus-sun-exposure*

Protect yourself

If you have lupus, protecting yourself from sun exposure is an essential part of managing your condition. Many people with lupus experience photosensitivity or unusual sensitivity to sunlight. This can trigger symptoms such as skin rashes, itching, and burning. Excess sun exposure can also cause flares in systemic lupus, triggering symptoms such as joint pain, weakness, and fatigue. In some cases, it can even cause internal organ damage.

The risks of UV radiation

Ultraviolet (UV) light is a type of invisible radiation that’s present in sunlight. There are three types: UVA, UVB, and UVC. According to research published in Autoimmunity Reviews, UVB rays seem to cause the most problems in people with lupus. UVA radiation can also contribute to symptoms.

If you have lupus, exposure to sunlight may trigger symptoms such as:

- lupus rash or lesions
- fatigue or weakness
- joint pain
- internal organ swelling

Wear protective clothing

To protect yourself from UV radiation, wear sun protective clothing that reflects or absorbs sunlight before it reaches your skin.

UV rays can pass through thin, light-colored, and loosely woven fabrics. For optimum protection, wear tightly woven, dark-colored, long-sleeved shirts and pants, as well as wide-brimmed hats. Certain types of fibers also provide more protection than others. Unbleached cotton absorbs UV rays, while polyester and silk with a high sheen reflect UV radiation. You can also find high-tech "sun protective clothing" designed to block UV rays at many sporting goods stores.

Ultraviolet protection factor (UPF)

Sun protective clothing has a rating, known as its ultraviolet protection factor (UPF). This denotes the amount of UV radiation absorbed by its fabric. Look for clothing that’s labeled with a UPF of 25 to 50 or higher.

Sun protective clothing can lose its effectiveness when it’s stretched, weathered, or over-washed. Be sure to take proper care of it and replace it when it wears out.

Choose the right sunscreen

In addition to wearing protective clothing, cover exposed skin with sunscreen. Look for sunscreen that:

- has a sun protection factor (SPF) of 30 or more
- provides broad spectrum protection, blocking UVB and UVA rays
- contains physical blockers, such as zinc oxide and titanium dioxide
- is hypoallergenic

5 Tips for Summer Travel

Source: *http://www.lupuschick.com/5-tips-summer-travel-lupus/*

Thank goodness it is finally summer! The sun is out, you have planned days off, you packed a bag, and are ready for the adventure of a lifetime. However, living with Lupus or any chronic illness can sometimes put a damper on your summer holiday. When planning your vacation, think about what you would want the vacation to look like if you were having a "good" Lupus day. Consider the things you would want to do: swimming, walking the beach (maybe in the evening?), going to historical sites, etc. Now, think about how you could best enjoy your vacation while having a "bad" Lupus day. Instead of running around visiting a bunch of landmarks, maybe you could take a bus tour, or sit in a cafe with a book, people watching. Think about which of the more demanding activities are the most important to you, and which can be replaced with something calmer. Then, when your vacation comes along, you can tackle it effortlessly and have "go-to" options on your high energy days or low energy times.

Packing A Bag For the Trip

This is essentially the most challenging part of the vacation. It would be wise to start packing your bag or bags days in advance. Packing ahead of time allows you to rest your body days before the start of the trip. Frantically packing the night before will only stress you out. If you are driving, pack your car ahead of time if possible. Include in your car a cooler with water and snacks to keep your sugar levels normal and your body hydrated. Make a list with everything you will need and check items off as you go. It would also be smart to include an emergency bag. This could have items in it such as Advil, your daily medications, a water bottle, lotion, wet wipes, snacks, loose clothing, or a blanket.

Research/Plan an Itinerary

Before you leave on your trip, research what the closest hospitals are around the location where you will be that accept your insurance. You can also jot down the name of an emergency walk in clinic, just in case. You never know when or how horrible a bad pain day will be. Decide what you think you would want to do on your bad pain days and good pain days. Having a list of activities to do during your vacation that can fit with how you are feeling will benefit your overall vacation experience!

The Flight or Drive to Your Destination

If you are flying, try to pre-board. You can attempt to walk up to the check in and tell them why you need to pre-board. Having a doctor’s letter can certainly help. Buy a decent travel pillow and pair of headphones. Bring luggage on wheels whether you are flying, driving, or taking a train. If you are driving with someone and need to take a break, do so. Tell them you need them to drive, or you need to get up and walk around. Do not wait to feel the ill effects of pushing yourself too hard.

The Vacation Part

Enjoy yourself! Even if you are having a not so great pain day. Prioritize what you want to see and experience. This way you have a plan of attack and do not overdo it and cause yourself to be in a lot of pain during day 1 of the trip. Be realistic and mindful of your body and energy level. You are the only one who knows how much energy or what food you can eat. If you are not comfortable or need to make sure you do not have an allergy to something, be sure to speak up! Regardless of where you go or who you are with, make sure you alert them to your conditions and what those conditions mean for you. Let the people around you know what they should expect and need to do if something were to happen. It is also handy to keep a printed document in your wallet that lists your conditions and current medications, plus allergies.

The Journey Home

All vacations come to an end at some point. I am sure you miss your bed and home. Hopefully, during your vacation you were able to listen to your body. You know your body better than anyone else and you know the consequences of ignoring your body's warning signs. If the vacation did not go as planned, I hope you rest when you get home. And remember to not push yourself past your limit.

Traveling when you have lupus does not have to be hard. It just takes a little extra planning by making sure you have all your supplies.

Recipe: Shrimp Ziti

Ingredients

- 1 lb. ziti or rigatoni
- 3 garlic cloves
- 1 14.5 oz can crushed tomatoes
- 2/3 c. half-and-half
- 1 lb. (31-to 40-ct.) peeled, deveined shrimp
- 1 c. frozen peas
- deep 12-inch skillet

Directions

- Bring a pot of water to a boil and cook 1 pound ziti or rigatoni as label directs. While pasta cooks, work on sauce.
- Chop 3 garlic cloves. Add to deep 12-inch skillet, with 3 tablespoons olive oil, and cook on medium heat for 3 minutes, stirring.
- Add 1 14.5 ounce can crushed tomatoes, and 2/3 cups half-and-half to skillet. Heat to a simmering, then simmer for 2 minutes, stirring.
- Add 1 pound peeled, deveined shrimp, 1 cup frozen peas, 1/4 teaspoon salt, and 1/2 teaspoon black pepper to skillet. Cook until shrimp are cooked, about 5 minutes.
- Serve pasta with sauce. Garnish with sliced green onions, if desired.

The recipes used by Lupus Canada have been reviewed and approved by Heather Penney, Registered Dietitian.

Source: https://www.goodhousekeeping.com/food-recipes/easy/a44228/easy-peasy-shrimp-ziti-recipe/

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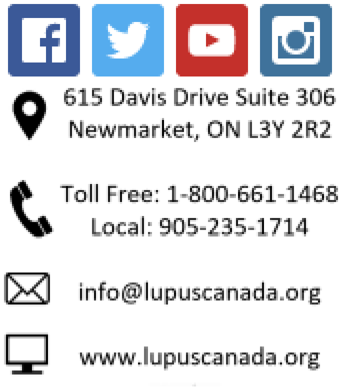

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Working together to conquer lupus

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