

Let's Talk Lupus

November Monthly E-Newsletter

LUPUS
CANADA
Life Without Lupus

With Thanksgiving being over and the holidays being next month, it is crucial to take time to relax. This month on November 11th, Canadians will be remembering and acknowledging those who fought and continue to fight for our country. Whether it is by wearing a poppy, visiting a memorial, or taking two minutes, ensure that you pause and reflect on the brave soldiers who stand bravely to preserve our nation's freedom.

On November 3rd we turned back the clocks one hour, as daylight savings returned. For those who rely on a routine, sometimes transitional periods or slight changes can affect your health. Be sure to wake up at the same time, eat a healthy breakfast and do some light exercise. It is easy to get so busy that you forget to take care of yourself so, for this reason, Lupus Canada will be focusing on 'relaxation', this month.

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GIVINGTUESDAY™

On December 3rd Lupus Canada celebrates Giving Tuesday. This day focuses on the importance of globally recognizing and supporting important causes. Lupus Canada is dedicated to bringing awareness and advocacy to not only lupus patients but also communities. We are thankful for the donations we receive that allow us to maintain our work and research. Giving Tuesday provides us with the chance to unite with other organizations, charities and people in empowering each other to make a positive change.

Help us reach our goal of \$5,000! Please consider donating to Lupus Canada by visiting our website (www.lupuscanada.org/giving-tuesday/). If you would like to learn more about this global day of recognition please visit <https://givingtuesday.ca/>

On behalf of all Canadians living with lupus we thank you in advance for your contribution!

LUPUS AND FATIGUE:

Source: https://www.hss.edu/conditions_lupus-and-fatigue.asp

Fatigue is a common symptom of lupus, everyone who lives with lupus will experience persistent and severe fatigue. When lupus patients experience fatigue, it is not a matter of taking a nap or attempting to go to bed earlier. Severe fatigue means that it does not matter how much one rests, they will still be exhausted and will not feel refreshed. The more a person experiences being severely fatigued, the more chronic it becomes. Dr. Berman defined fatigued as "an overwhelming, sustained sense of exhaustion and decreased capacity for mental and physical work". Whereas, chronic fatigue is defined as, "unpleasant, unusual, abnormal or excessive whole-body tiredness, disproportionate or unrelated to activity or exertion and present for one month". For example, someone living with lupus will become exhausted after taking a shower or making dinner. Consequently, it is imperative that lupus patients assess and address other factors that may contribute to your fatigue such as: thyroid problems, stress, anemia, inflammation, infections and low vitamin D levels.

It is difficult transitioning from having an organized and active lifestyle to living with lupus. From having daily tasks that you could once complete to only being able to fulfill half the list can be discouraging. An activity that can be beneficial to lupus patients is meditation. Having a period where you can focus on breathing properly will alleviate stress and allow you to cope with your lupus.

BENEFITS OF MEDITATION:

Source: <https://www.healthline.com/nutrition/12-benefits-of-meditation>

Meditation is helpful for anybody; however, lupus patients can specifically benefit from this activity due to joint inflammation, mental health, and coping with stress. According to *Healthline*, "meditation is a habitual process of (1) training your mind to focus, (2) redirecting your thoughts, (3) increasing self-awareness, and (4) becoming aware of your surroundings". Meditation leads to a more positive outlook on life, self-discipline, and a more consistent sleep pattern. Below are nine science-based benefits of meditation:

1. Reduce Stress:

Being mentally and/or physically stressed can increase levels of stress of the hormone cortisol which releases inflammation promoting chemicals; thus, resulting in disrupted sleep, depression and anxiety.

2. Controls Anxiety:

Meditating results in less stress which results in reducing symptoms of anxiety disorder and less anxiety in general. Lupus patients often experience anxiety regarding every facet of their life. Therefore, meditation can help those living with lupus cope with job related anxiety in high-pressure work environments.

3. Promotes Emotional Health:

Meditation can also lead to an improved self-image and more positive outlook on life. Research shows that maintaining an ongoing habit of meditation may help you maintain these benefits long term.

4. Enhances Self-Awareness:

Meditation may help you develop a stronger understanding of yourself, helping you grow into your best self. Additionally, it allows you to think about how you relate to those around you and teaches you to recognize thoughts that may be harmful or self-defeating.

5. Can Generate Kindness:

Meditation increases positive feelings and actions toward yourself and others. Certain types of meditation begin with developing positive thoughts and feelings toward yourself. People learn to extend this kindness and forgiveness externally.

6. Improves Sleep:

Meditation allows you to fall asleep sooner and for a longer period of time. It relaxes the body, releases tension, and places you in a peaceful state.

7. Help Control Pain:

Perception of pain is connected to state of mind and it can be elevated in stressful conditions. Meditators showed a greater ability to cope with pain and even experienced a reduced sensation of pain.

8. Can Decrease Blood Pressure:

Meditation can also improve physical health by reducing strain on the heart. In part, meditation appears to control blood pressure by relaxing the nerve signals that coordinate heart function, tension in blood vessels and the "fight-or-flight" response that increases alertness in stressful situations.

9. You Can Meditate Anywhere:

Meditation does not require specialized equipment or space. If your regular work and home environments do not allow for consistent, quiet alone time, consider participating in a class. This can also improve your chances of success by providing a

supportive community.

YOGA AND LUPUS:

Source: <https://www.yogajournal.com/lifestyle/yoga-and-lupus>

Due to the impact of joint health and flexibility, yoga has a role in helping to manage lupus. Systemic Lupus Erythematosus can affect the joint and almost every other bodily system, including skin, heart, lungs and kidneys. To improve joint health when symptom-free, you should focus on proper alignment of the joints, creating maximum space in the joint and putting the joints through a full range of motion. Yoga is a great outlet as, like lupus, can be personalized towards you and your ability.

SLEEP AND LUPUS:

Source: <https://lupusnewstoday.com/2019/05/09/sleep-disturbances-disorders-cpap-pain/>

Poor sleep patterns and quality is common for lupus patients. According to a 2014 study, up to 85% of lupus patients have sleeping disorders. It is also hard to find medicine that coincides with the disease. Down below are some tips for sleeping better provided by The Lupus Foundation of America and Lupus News Today:

1. Put away devices 30 minutes to an hour before bedtime.
2. Keep your bedroom a few degrees cooler than the rest of the house.
3. Exercise daily but ensure it is not right before you go to sleep.
4. Take a warm bath to help you relax.
5. Limit naps to less than an hour.
6. Limit caffeine in the evening hours.
7. Keep a journal to track how much sleep you are getting and try to identify trends or possible symptoms.
8. SleepyTime Tea: chamomile, spearmint, and valerian assist with easing your body into a relaxing state.

9. ASMR sleep videos: sometimes listening to soft music and sounds can allow you to achieve a restful sleep.

The amount of time someone living with lupus sleeps and the quality of the sleep they have, has a major impact on their daily life. Lack of sleep impacts how one thinks, learns, interacts and works. A continuous lack of sleep can lead to health conditions, so it is imperative that lupus patients find tactics that assist with transitioning your body into a state of relaxation to assist with getting an adequate amount of rest.



Source: <https://www.lupus.org/news/exciting-research-news-from-13th-international-congress-on-lupus>

Exciting Research News from 13th International Congress on Lupus:

In April 2019, the global lupus community gathered at the 13th International Congress on Systemic Lupus Erythematosus. This event allowed world-renowned lupus researchers to present critical research findings. The meeting was entitled, "LUPUS 2019: Gateway to the Future", and was full of exciting news on topics such as worldwide representation on clinical trials, disease, heterogeneity, patient engagement and precision medicine.



Lupus Canada is excited to welcome Susan Smart who joins us in the role of National Fundraising Manager.

Susan comes to our organization with over 25 years of progressive leadership and sales experience in both for profit and nonprofit sectors. Susan is a welcomed addition to our National team.

Susan is keen on making connections with our e-newsletter community who are over 6000 members strong! She encourages communication especially on ideas of how to



generate more involvement from those *not* living with lupus so that we can further education, create more awareness and eventually grow our donations. Susan is passionate about Lupus Canada and wants to see even more funding directed towards research and supporting the annual Scholarship program.

To speak with Susan about Corporate sponsorships, third party events and event sponsorships please email her at susan.smart@lupuscanada.org or at 1-800-661-1468.

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To order please visit www.lupuscanada.org/toques or call 1-800-661-1468.



My name is Paige Sharpe, I'm 15 years old from Toronto Ontario and I've just been diagnosed with SLE that is effecting my CNS.

My lupus story begins about 4 months ago when I developed the butterfly rash across my face. I had a checkup with my doctor 3 days after I developed the rash and my doctor diagnosed me with contact dermatitis, no big deal I used the cream my doctor prescribed me, but the next 2 days was where everything went downhill. I started to develop extreme fatigue and steady joint pain followed by a pounding headache. My mom made the decision to take me to the ER, when it got so bad that my feet and hands were turned in and I could barely move them/walk. When we got to the ER all my blood test and vitals came back perfectly fine so the doctors had no answers. We were sent home with tylenol but that didn't take any of my pain away. My mom was eager to find answers on why her athletic, intelligent and bubbly daughter was falling apart at her feet. About 2 weeks before my rash made its peek I started noticing people calling my name that weren't there and constant dizzy spells. I honestly didn't think anything of it and just played it off as over stressing. 3 ER's and constant frustration later I became very sick with a spiking fever. My mom decided to take me to Sick Kids in Toronto, 12 tubes of blood later I found out I was testing positive for ANA enzyme. I was admitted in the hospital for 5 days with a whole team working on my case. Psychologist, Rheumatologist, Pediatricians, Optometrist, every doctor was baffled on how quick my body was falling apart. After a long meeting/ examination with the Rheumatologist and Psychiatrist about me hearing and seeing things that weren't there, a MRI was ordered. My team then diagnosed me with SLE attacking my brain... my heart sank. so what now? What happens now? My mom's face turned white and instantly turned into tears. Because the SLE is attacking such a big organ they decided to put me on the max dose of Prednisone and cyclophosphamide (low dose form of chemo therapy) that I go once a month to get through IV. My whole life has changed because of SLE. I never knew how to swallow a pill before and now I take a total of 18 a day. Adjusting to my new life, with my new best friend that lives in my brain has had its ups and downs, I never thought that I could ever get so low but there was a time I was at a low point where all I wanted to do wake up and sleep it off all day. I talked to my therapist about it and she diagnosed me with depression. She also talked to me about meeting other teens with lupus which I was totally for. I am doing a lot better now but there's always that pain that I'm fighting through. The sun is one of my biggest enemies. I cannot go in the sun without the getting a flare across my face and on my legs. I have been forced to put my whole life on hold because I cannot concentrate or write or read and long and short term memory loss is also a factor that I will have to reteach myself. I do not attend school but I stay at home teaching myself about my disease and living with my lupus. Lupus has affected my sports. Going from your average athletic 15 year old girl playing on every team in and outside of school she can, to not even being able to climb up the stairs without having extreme chest pain and shortness of breath. Lupus has become who I am now. I live and learn with it, but I wouldn't be able to relearn everything again without the support of my friends, coaches, family and doctors and therapist. I may have Lupus but I won't let it have me.



And that's my lupus story. Sincerely Paige

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

RECIPES:

Baked Salmon

Another great one pan meal loaded with SUPERFOODS for this anti-inflammatory meal plan! Salmon is rich in Omega 3's, blueberries are rich in antioxidants and Vitamin C, and Brussel Sprouts are high in Vitamin K! Whole 30 friendly. This one pan meal, superfood baked salmon recipe is ready in 20 minutes and packed full of nutrients. A nourishing, whole 30 friendly, flavorful meal!

Ingredients:

- 3 to 4 salmon fillets (4-5 ounces each) or 16 oz fillet (We use Sizzlefish Atlantic Salmon)
- 2 cups brussels sprouts (quartered)
- 1 cup fresh blueberries (or frozen)
- 1/4 to 1/3 cup chopped fresh basil
- 1/4 to 1/3 olive oil (divided)
- 3 tbsp balsamic vinegar
- 2 cloves or 1 tsp minced Garlic
- 1/4 to 1/2 tsp crush black Pepper
- Sea Salt (divided)
- 2 Lemons, one juiced and one sliced



How to Make It:

Step 1: Preheat oven to 400F

Step 2: Clean your salmon fillets and place on lined sheet pan.

Step 3: Clean and chop your Brussel sprouts. Place on pan with salmon.

Step 4: Generously sprinkle sea salt on top of salmon and veggies. Set aside.

Step 5: Next, place your blueberries in a bowl. Mash with fork a bit.

Step 6: Add in 1/4 cup olive oil, 1/4 tsp salt/pepper, your basil, garlic, and balsamic vinegar. Mix all together.

Step 7: Drizzle another 2 -3 tbsp olive oil over your salmon and Brussels sprouts.

Step 8: Spoon the balsamic basil blueberry mixture over salmon fillets.

Step 9: Squeeze fresh lemon on top of salmon and veggies. Place lemon slices on top of veggies on the sheet pan. Sprinkle with extra black pepper.

Step 10: Place in oven and bake for 15 minutes.

Step 11: Broil for 1 -2 minutes extra to make Brussels sprouts and baked salmon skin extra crispy.

Step 12: Remove from oven. Serve and enjoy!

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


Source: <https://www.cottercrunch.com/superfood-baked-salmon-recipe-paleo/>


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