



## Let's Talk Lupus

December Monthly E-Newsletter

May this month bring positive changes into your life! Whether it is getting ready for exams, volunteering, or spending time with family, this time of year can be extremely exciting while at the same time exhausting. It is hard to not have a smile on your face when everything whether it is the snow or Christmas lights, looks so pretty. Whether it is listening to the holiday music, enjoying a festive meal, or spending time with family, please be sure to enjoy yourself!

Are you struggling to think of a gift for someone or are inspired to think of an act of kindness this holiday season? Think of Lupus Canada during the holiday season and visit our website on different ways to donate <https://www.lupuscanada.org/ways-to-donate/>

Donations allow us to keep working towards funding scholarships for students living with lupus, providing research grants and continuing the conversation around lupus.

This month, Lupus Canada wants to focus on 'assistance'. Accepting assistance and living with lupus is vital. The holidays are already tiring so, even if it is hard to admit, for your health and happiness we encourage you to plan, prioritize and delegate. Doing this will allow you to have time to have fun, relax and reflect on your year.

**DONATE NOW**

your gift makes a difference

**GIVINGTUESDAY™**

Lupus Canada is thrilled once again to be participating in GivingTuesday!

On Tuesday December 3rd join us for another record breaking year and kick off the holiday giving season. Last year more than 6,500 partners in Canada celebrate Giving Tuesday and millions of Canadians supported their favourite charities.

We hope that you will join us in achieving our goal of raising \$5000 this year on Tuesday December 3 by making a donation to [www.lupuscanada.org/giving-tuesday](http://www.lupuscanada.org/giving-tuesday)

Together we can make a difference in the lives of those living with lupus!

## MANAGING HOLIDAY STRESS:

holidays  
schedule  
plan  
stress  
relax

*How do you manage the stress of the holiday season and the many events and activities that go along with it?*

Source:

<https://www.lupus.org/node/1534>

The holiday season can be stressful for many and living with lupus on top of that can make it even more difficult. I have found that starting my Christmas shopping early is helpful, that way I'm

not running around at the last minute. I've also found that with the many family members we have, to communicate ahead of time a plan for Christmas dinners/parties etc. If I know exactly what we are doing and where we are going at least by the beginning of December, then I feel a little less stressed and have time to be prepared. **The most important thing is to rest when you need it and to not overfill your plate.** – Roxi

For the holiday season, I am in college, so I have all my finals coming up. It can get very stressful to cram for my exams and work at the same time, both full-time. **The way I manage it is do one thing at a time.** If you try to do everything at once, you are going to psych yourself out, so the best thing to focus on is the primary thing and work from there. I also love to have an hour of "me" time and lie down and listen to classical music by the fire. It's very relaxing and helps my stress levels go down. – Kyra

**Mindfulness.** When I start feeling overwhelmed during the holiday season, I try to step back and look at the reasons why. Most of the time, I realize it is high expectations I have set for myself. I try to remember that the people in my life are understanding and will not be offended or disappointed if I have to cancel, opt out, or cut back with attending, hosting, or cooking for a holiday event. Also, getting organized! Nothing makes you feel less stressed during the holidays than a good plan! – Kristin

**I handle the stress of holiday shopping by picking a time to shop when the stores are less crowded.** I often take 20 minutes of "me" time to just meditate and listen to relaxing music. I also love spending time with a good friend. It can be a very stressful season, but I often de-stress myself. I usually try to sleep longer, and walking has always been an excellent way to de-stress. I don't take on more than I can handle. I love sharing the responsibility of meal preparation. This takes the load off me. When you have lupus, it can be overwhelming. Lastly, I always try to visit

someone in the nursing home and show them love. I find this removes so much stress at the holidays. I love helping others. -- Sylvia

## REACHING OUT FOR HELP:

*Source: Caring for someone with Lupus – Lupus UK*

Lupus affects each person differently, therefore, the assistance one may need will differ depending on the circumstance. Understanding the significance of planning, prioritizing, and delegating will allow you to realize what you may need help with, and this will allow you to communicate with others easier. Planning requires you to think of everything you have to accomplish and thinking of ways to schedule your day in a manner that allows you to still take care of yourself. Secondly, prioritizing consists of dividing the tasks and activities in two groups: the must or needs and the things that can wait. Lastly, delegating requires one to use their resources wisely so that you can save your time and energy- something that is critical for lupus patients.

If you are an independent person or newly diagnosed with lupus, it can be difficult to accept that you need assistance or to transition to having a caregiver. Further, when you do accept assistance a tension can develop, especially if it is a friend or partner who is now being a caregiver. Communication is needed whenever someone accepts help, otherwise, bitterness or frustration can develop. Below are tips and advice from, *Caring for Someone with Lupus: Lupus UK*, that considers the perspectives from both the person living with lupus and caregiver:

### **1. Caregiver: Looking After Yourself**

It is easier to cope with the pressure of caring for someone if you are also caring for yourself. By maintaining both emotional and physical health, you will be able to care for someone to the best of your ability. So, take a break and make sure to have time to relax.

### **2. Person Living with Lupus: Accepting Help**

It can be hard to accept and cope with dependence. If you say you are fine or you are managing, people may not think to ask again which can result in missing out on a valuable source of support.

### **3. Overall Pointers and Tips:**

Do what you can and learn as much as you can. People are more willing to accept help if they feel understood. Additionally, be sure that the person living with lupus attends all medical appointments. Overall, just do your best, be organized and be patient.

## AVOID SAYING THIS TO LUPUS PATIENTS:

Source: <https://www.healthline.com/health-news/ms-12-things-not-to-say-022814#4>

Living with a long-term health issue can result in friends, relative or colleagues wanting to assist you but can result in them being insensitive. Here are some statements to avoid while speaking to someone with a health condition:

- *"Disease is all in the mind."*
- *"You do not look sick to me."*
- *"I know exactly what it feels like"*
- *"You are so brave."*
- *"You should try this."*
- *"It could be worse."*
- *"I know someone who has that, and they are fine."*
- *"Did you get this because..."*
- *"I am sorry."*
- *"Have you lost weight?"*

Whether it is explicitly stated or not, saying comments that insinuates (1) if someone changes their mindset they will feel better, or (2) trying to place blame on the person's previous actions, or (3) attempting to measure a person's suffering, will result in the person feeling bad about their illness. According to the *Centers for Disease Control and Prevention*, "a quarter people living with chronic conditions say that they experience significant limitations in daily activities, but many of those people do not have visible symptoms." Symptoms such as weight loss could be perceived as a positive change, however, do not assume that all weight loss is welcomed and reflect on the reason why this may be happening.

Disease varies from person to person, although someone may physically seem okay, do not assume that emotionally, mentally or internally they are. Again, although you may have the right intentions, a simple statement can make someone feel misunderstood.

Further, if you truly want to assist someone living with lupus just asking how they are could be all they need, for example saying "I am here for you" may be all they need to hear. Remember, leave the medical advice to the professionals and before saying something think "will this be helpful?"

## HELPING SOMEONE WITH LUPUS:

Source: <https://lupus.newlifeoutlook.com/help-someone-with-lupus/>

It can be difficult seeing someone you love struggle. People often times, try to always

ask if they can do anything for the person or bring them something. However, one of the best ways to help someone with lupus is simply by listening and demonstrating sympathy. Remember, you do not need to understand or experience similar feelings or events as someone to be a good listener. Just show compassion and be attentive to the person.

Sometimes, people try to be a good friend and listen, however, it becomes uncomfortable. Lupus patients can be tentative to ask for help or communicate with others as people try to fix or help them instead of listening to them. Moreover, lupus patients may reject help when (1) people only want to physically help instead of emotionally, (2) people lack an understanding of lupus, and (3) people's unawareness of lupus become judgemental. The correlation of these three reasons results into people trying to tell lupus patients how to get better and how to cure themselves. Although the intentions are present, most people do not understand the different ways to help someone or in general what offering help to someone can entail. *NewlifeoutlookLupus*, has three suggestions of how to help someone living with lupus:

#### ***Considerate Invitations:***

Offer to invite the person living with lupus to activities centered around good weather or indoor activities such as watching a movie or working on a craft. Do not invite them to activities that will not be beneficial to them, such as going to participate in a heavily exercise centered activity.

#### ***Really Listen:***

Nothing makes people feel loved and nurtured more than feeling that what they are saying matters to someone. When people communicate pain and a week later you do not have any idea what they are going through it is upsetting. Do not feel like you have to try and relate or turn it around somehow into a story about you.

#### ***Offer to Help with Small Things:***

Tasks that may seem small to you may in fact be quite daunting to those with lupus. Make an effort to call and ask if the person needs anything picked up. Running an errand is helpful to those who are living with lupus.

#### ***Paraphrase:***

Paraphrasing is a way of reflecting back what you heard. This is an effective strategy to use as the other person will know that you are listening and understanding. It leads to more expanded, supportive conversations.



Our inaugural *Laughs for Lupus* held in May was so well received we've decided to host another fun comedic event in May 2020! Stay tuned for details on date, location and talent. We hope you'll be able to join us for a night of fun and fundraising, all in support of Lupus Canada.

***Looking for that perfect stocking stuffer? We have the perfect gifts for that special someone.***



***Get your lupus toque for only \$15***  
<https://www.lupuscanada.org/toques/>

***or a lupus lanyard for \$10***  
<https://www.lupuscanada.org/lanyards/>

## ADVOCACY INITIATIVES:

This past October, Lupus Canada undertook our first national election campaign, seeking to strengthen federal supports for those living with lupus. With your support we sent over 325 letters to local candidates in the federal election. These letters helped to raise awareness about lupus and about the necessary changes needed to the EI Sickness Benefit and Canada Pension Plan – Disability component. A big thank you to all those who took the time to send a letter and share.

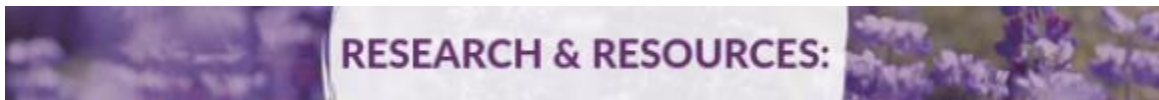
But our work isn't over. We still need to keep our elected officials' feet to the fire, if we are ever going to see these changes. Lupus Canada will be organizing another letter writing campaign targeting the newly elected Members of Parliament to support our campaign. Stay tuned for information, as our campaign develops.



Source: <https://www.medicalnewstoday.com/articles/319485.php>

"Did you know that researchers found that women who met the criteria for PTSD were more likely to develop SLE compared with women who had experienced no trauma?"

"The results revealed that women who had been exposed to any kind of trauma - regardless of whether they had symptoms of PTSD - had a 2.87 times greater risk of SLE. According to the researchers, their findings provide further evidence that psychosocial trauma may increase the likelihood of autoimmune disease. Dr. Andrea Roberts states, 'Our results add to considerable scientific evidence that our mental health substantially affects our physical health, making access to mental healthcare even more urgent.'"



Source: <https://www.lupus.org/news/study-finds-lupus-manifests-differently-and-more-severely-among-racial-and-ethnic-groups>

*Study Finds Lupus Manifests Differently and Severely Among Racial & Ethnic Groups*

Lupus Foundation of American released an article, "Study Finds Lupus Manifests Differently and More Severely Among Racial and Ethnic Groups" on June 6, 2019. In the US, lupus is more prevalent among women and racial/ethnic minority groups. Researchers studied 774 people with lupus in California Lupus Surveillance Project in the San Francisco area to investigate racial/ethnic differences in the prevalence of lupus manifestations and in the risk and timing of development of sever lupus manifestations.



**Lentil Roast with Balsamic Onion Gravy**

## Ingredients:

### *For the Lentil Loaf:*

- 1 tbsp vegetable oil
- 1 small onion, minced
- 3 cloves of garlic, minced
- 2 medium portobello mushrooms, finely chopped
- 1 medium carrot grated
- 400 g tin of cooked kidney beans, rinsed
- 400 g tin of cooked puy lentils, rinsed
- 1 tbsp gluten-free tamari soy sauce
- 2 tbsp mixed dried herbs
- 4 tbsp nutritional yeast
- Black pepper, to taste
- 135 g rolled oats, (gluten-free, if needed)



### *For the Balsamic Onion Gravy*

- 1 low-salt vegetable stock cube
- 1 medium red onion, finely sliced
- 2 tbsp vegetable oil
- 1 tbsp coconut sugar or brown sugar
- 1 tbsp arrowroot powder
- 200 ml red wine
- 3 tbsp balsamic vinegar
- 3 tbsp gluten-free tamari soy sauce, or coconut aminos for a soy-free version

## How to Make It:

### *To Make the Lentil Loaf*

*Step 1:* Preheat oven to 180c / 350f and line a loaf tin with greaseproof paper.

*Step 2:* Heat the oil in a frying pan and sauté the onion and garlic until soft. Add the mushroom and carrot and cook for another 5 minutes until softened.

*Step 3:* Add the rest of the ingredients and use a masher to combine. Don't over-mash, just enough so that the mixture comes together. Add a drop of water if the mixture is too dry, if it's too wet, add more oats.

*Step 4:* Transfer the mixture into the loaf tin and cook for 40-45 minutes until the outside develops a crust and the inside is firm.

### *To Make the Gravy*

*Step 1:* Prepare half a liter of vegetable stock with the stock cube and set aside.



*Step 2:* Add the oil to a frying pan and sauté the onion with the coconut sugar for 10 minutes.

*Step 3:* Once it's caramelized, add the arrowroot powder to the pan and stir for a few minutes to combine.

*Step 4:* Pour in the wine, balsamic vinegar and tamari sauce and simmer until the stock is reduced by half.

*Step 5:* Add the vegetable stock and simmer again for 10 minutes until you are left with a thick, dark gravy.

*Step 6:* Option- for a smooth gravy, blend for a few minutes until no lumps remain. Serve with the lentil loaf and roast vegetables.

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

Source: <http://wallflowerkitchen.com/lentil-roast-with-gravy/>

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