



Let's Talk Lupus

October Monthly E-Newsletter

It is always exciting to start a new month, especially when you can smell the autumn air and hear the leaves crackling under your feet! On October 14th we celebrate Thanksgiving, a time to give thanks and show gratitude to those you love. So, take advantage of this opportunity to give to others and to show your generosity.

Additionally, World Mental Health Day is October 10th, a day which focuses on raising awareness and allows others to share their efforts with the community. This day is dedicated to strengthening information systems, providing necessary care and promoting mental health.

With these two events in mind, the focus of this month will be 'limitations and adaptiveness'. Holidays can sometimes cause stress and make people feel pressured to fulfill obligations. It is essential to be self-aware of your boundaries and to always put your health and needs first.

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ADVOCACY INITIATIVES:

Lupus Canada is embarking on an advocacy campaign during the federal election and we need your help!

Do you want better support for Canadians living with lupus? Do you want to make it easier for Canadians with lupus to be eligible for federal government support programs? Well we have an advocacy campaign for you!

Join Lupus Canada as we try to make changes to the EI Sickness Benefit and Canada Pension Plan Disability Component. Find out more about our campaign here. (link to <https://www.lupuscanada.org/federal-election/>)

How can you help?

- Send a letter to your local candidates running in your riding by click here (link to <https://www.lupuscanada.org/advocate-for-yourself/>).
- Spread the word as wide as possible! Share with your family, friend, colleagues and peers with lupus.
- Share via your own social media.

- Share, like and retweet Lupus Canada's social media.

Have questions? Please fill them out on our federal election advocacy campaign website (link to <https://www.lupuscanada.org/federal-election/>)

ACKNOWLEDGING YOUR LIMITATIONS:

Source: <https://www.psychologytoday.com/us/blog/evolution-the-self/201707/yes-you-can-t-why-you-should-affirm-your-limitations>

Although resilience is an important characteristic to have, there are also times when accepting your constraints is equally, if not more, important. Striving to do your best requires a balance of these two concepts, Lean F. Seltzer states, "it is important to be aware when you can extend and accept your limitations".

If one does not acknowledge their limitations it can lead to stress and disappointment. Limitations tend to derive from having an expectation. When one confronts the reality that perhaps they are unable to complete or fulfill a task it is hard and discouraging. Therefore, before one can accept their limitation, they must grieve their expectations. Once you have accepted your limitation is it important to think of challenges that work for you, something that will allow you to work hard towards a goal.

ADAPTING TO YOUR LIMITATIONS:

Source: *Coping with Lupus: A Practical Guide to Alleviating Challenges*

William B. Salt says, "you do not have to like your limitations in life, but- for healing to occur- you do have to accept them." Everyone has limitations in life, some more severe than others, so it is vital to listen and learn to use your body. Some people may think, "what do you mean learn to use our body?" Well, learning to use your body entails figuring out your strengths and weaknesses. What does your body cope with well and what makes it tired? No matter the circumstance you are in, understanding your body is critical.

Living with lupus may mean relearning and understanding your body. Symptoms such as increased fatigue, inflammation, and joint pain are normal. In order to prevent these, be aware of the possible factors that prevent and worsen these symptoms. Thus, people living with lupus may have to make changes and acknowledge their limitations in life. That being said, knowing your limitations does not equate to giving up. It means adjusting accordingly so that you are not getting by but are living the best life you can. Refute the notion, although it is challenging, that you are powerless. Further, try to mentally detach yourself from the disease. Remember that although you live with lupus, it is not the only part of who you are. For instance, when some has the flu, it is not apart of who they are. Kristina Page recommends picturing yourself as entirely two separate beings (1) lupus and (2) you. By separating the lupus from who you are, it allows you to put negative feelings toward lupus and not yourself, and this avoids self-hatred. Down below are some suggestions from the book, "Coping with Lupus", that a person

living with lupus can integrate into their daily life:

Listening to your body and not ignoring discomfort

Exercising to help increase joint mobility

Resting as long as necessary

Eliminating unnecessary activities to preserve energy

Learning how to plan and pace yourself

COPING WITH YOUR LIMITATIONS:

Source: <https://www.everydayhealth.com/lupus/helping-someone-adjust-to-lupus.aspx>

Lupus affects each person differently. Some people do not have limitations and do not have to adjust, while others do. Below are five different adjustments one can make to their homes to alleviate lupus flares and conserve energy:

1. *Climate Control:*

- Lupus patients can be sensitive to the cold which causes poor blood flow to their fingers and toes. Therefore, to keep body temperatures warm, it is a good idea to wear protective hand wear. Wearing mittens can be helpful to prevent stiff, numb, and even blue fingers.

2. *Getting to Appointments:*

- Asking a friend or family member to go to appointments with you can be very helpful. If mobility is a struggle you can consider special shoes, canes, walkers or devices that help with joint pain.

3. *Organization:*

- Patients with lupus can have cognitive issues also known as lupus fog, which is the inability to recall information. It is essential to make sure you are taking your medication, and if you feel as though you need a reminder ask a friend or caregiver to double check and ensure you are taking them. Further, perhaps consider a logical place to put things and buying a notebook to write things down.

4. *The Bathroom:*

- Basic activities are hard to complete for lupus patients, so it might be easier to install a raised toilet seat and safety shower railings.

5. Prevent Excessive Sunshine in Your House:

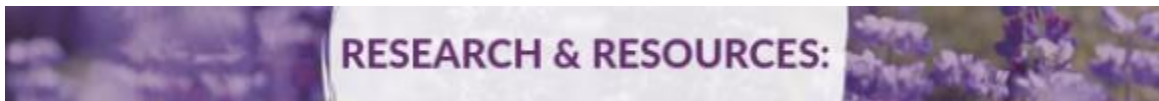
- Lupus can cause sensitivity to sun called 'photosensitivity' which can cause physical limitations. Lupus patients need to cover their skin with sun protective clothes and sunscreen. A helpful hint is to install awnings over sunny windows or keep blinds drawn.



Source: <https://creakyjoints.org/education/lupus-facts/>

"Did you know that lupus can look like other conditions?"

"Other conditions like rheumatoid arthritis, fibromyalgia, and Lyme disease share symptoms with lupus. Without a specific blood test pointing to lupus or other autoimmune conditions, it can sometimes take trial and error for rheumatologists to pin down the right diagnosis."



Source: <https://www.lupusresearch.org/new-treatment-approaches-supported-by-lra-highlighted-at-lupus-2019/>

Reviving an Old Drug to Treat Lupus:

Results from a team led by Dr. Mariana Kaplan of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), also point to a possible treatment for lupus—a drug originally developed as a therapy for Alzheimer's disease. The drug, idebenone, was not effective against Alzheimer's disease. But Dr. Kaplan and her colleagues reasoned that it might work against lupus.

In patients with the disease, mitochondria, the structures that serve as power plants for cells, malfunction. They release large amounts of damaging molecules known as reactive oxygen species and produce less energy. Idebenone neutralizes reactive oxygen species and can increase mitochondria's power-generating ability. The scientists tested idebenone in animals with lupus-like symptoms. The animals that received idebenone survived longer and suffered less kidney damage, a common problem in patients with lupus. Their mitochondria also performed better, and the animals showed less damage from reactive oxygen species. Future studies could include testing this drug in clinical trials in lupus.



RECIPES:

Gluten Free Savory Stuffing

Gluten free stuffing is easily adapted to your taste, tradition and items on hand. The better the ingredients, the better the end result, so use delicious homemade bread, if possible. Baked separately, this stuffing travels well.



Ingredients:

- 6 cups gluten-free bread cubes (about half a 2- to 3-pound loaf)
- 3 tablespoons extra virgin olive oil
- ½ cup chopped onion
- ½ teaspoon ground nutmeg
- 2 teaspoons sage
- ½ teaspoon marjoram
- ½ teaspoon salt
- 1 teaspoon pepper
- 1 cup chopped carrots
- 1 cup chopped celery
- 2 cups chopped and peeled apples
- ¼ cup dried cranberries
- ½ cup chopped pecans or walnuts, optional
- ¼ cup flaxseed meal
- 2 cups gluten-free vegetable broth

How to Make It:

Step 1

Preheat oven to 300 degrees. Line a cookie sheet with aluminum foil.

Step 2

Spread gluten free bread cubes in a single layer on prepared cookie sheet. Bake in preheated oven for 20 to 25 minutes or until cubes are dry. Turn the cubes once or twice during baking.

Step 3

In a large skillet, heat oil. Add onion and cook until tender and translucent, browning a bit at the edges. Add spices, carrots and celery, sautéing an additional 2 to 3 minutes. Set aside.

Step 4

Pour dried bread cubes into a 9×13-inch baking pan. Stir in sautéed vegetables and distribute throughout the cubes.

Step 5

Add apples, cranberries, nuts (if tolerated) and flaxseed meal, stirring gently until combined.

Step 6

Drizzle broth over mixture, stirring to coat (not soak) the gluten free cubes. You may need more or less gluten free broth to accomplish this, depending on what kind of bread used.

Step 7

Increase oven temperature to 375 degrees.

Step 8

Cover gluten free stuffing with foil and bake for approximately 30 minutes. For a crispy top, remove the foil for the last 10 minutes of baking.

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

Source: <https://www.glutenfreeandmore.com/issues/easy-and-delicious-gluten-free-dairy-free-thanksgiving/>

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