



Let's Talk Lupus

July Monthly E-Newsletter

LUPUS
CANADA
Life Without Lupus

Happy Summer! The sun is shining, and the temperature is quickly rising! On July 1st, Canadians around the country celebrated Canada Day. This holiday helps us to recognize the amazing privilege we have to live in this great nation – Happy Canada Day from Lupus Canada!

With International Self-care Day on July 24th, we encourage you to celebrate YOURSELF. Living with lupus should not deter you from living a dynamic and happy life. Self-care is a vital component to leading a healthy life and so, this newsletter will focus on self-care and wellness.

The COVID-19 pandemic has brought new challenges to everyone across the globe, no one was spared from its impact. At Lupus Canada we will continue to work diligently to support our lupus community as we navigate this "new" normal and learn more about this virus.

DONATE NOW

your gift makes a difference



THE GIFT OF GIVING

HELP US CREATE A "LIFE WITHOUT LUPUS".

LUPUS
CANADA
Life Without Lupus

Lupus Canada hopes that you and your loved ones are staying safe during these challenging times. We thank you for your endless support and patience as we all work together to keep up to date on the implications regarding COVID-19 and people living with lupus.

With the challenges of COVID-19, donating now can have a profound impact for lupus patients. The pandemic has brought new challenges. Like all charitable organizations, we are struggling with funding during these unprecedented times. For these reasons, we would like to thank our current donors for all their support and ask for others to please consider Lupus Canada when thinking of charities to donate to.

Please view our Gift of Giving video we have made regarding donations and how every dollar can make a difference towards building a "Life Without Lupus".

GIFT OF GIVING VIDEO

LUPUS CANADA NEWS/EVENTS:



Lupus Canada has a special announcement!

Keep an eye out for our summer campaign running from July 8th to August 28th. We'll be revealing this summer campaign through an e-blast and on our social media platforms on July 8th.

Lupus Canada understands that during these unprecedented times it may be difficult to make a one-time donation. For these reasons, we have created a fundraiser that we hope will be fun for all to enjoy!

Through July 8th to August 28th help Lupus Canada improve the lives of people living with lupus!

Lupus Canada Launches New Website

In order to best serve our community we have streamlined our website to ensure we provide accurate, up-to-date relevant information in an easy to navigate site. To visit our new website please visit www.lupuscanada.org



WHAT DOES SELF-CARE MEAN:

Source: <https://psychcentral.com/blog/what-self-care-is-and-what-it-isnt-2/>

Self-care is any activity that we do deliberately in order to take care of our mental, emotional, and physical health. It seems simple but often self-care is overlooked. Good self-care is key to

improved mood and reduced anxiety and is also key to a good relationship with oneself and others. Self care is not something that we force ourselves to do or something we do not enjoy doing. It is something that refuels us, rather than takes from us, and most importantly it is not a selfish act. It is not only about considering our needs; it is rather about knowing what we need to do in order to take care of ourselves, being subsequently, able to take care of others as well. If we do not take enough care of ourselves, we cannot be in the place to give to loved ones either.

Self-care is key to living a balanced life, here are three golden rules:

- Stick to the basics. Find your own rhythm and routine as this will allow you to implement self-care forms that work for you.
- Self-care needs to be something you actively plan. It is an active choice and you must treat it as such. Add activities to your calendar and actively look for opportunities to practise self-care.
- Keeping a conscious mind is what counts. If you do not see something as self-care or do not do something in order to take care of yourself, it will not work as such. Be aware of what you do, why you do it, how it feels and what the outcomes are.

Basic Checklist That Can be Followed:

- Create a no list, with things you know you do not like.
- Promote a healthy and nutritious diet.
- Get enough sleep.
- Exercise.
- Follow up with medical care.
- Use relaxation exercises and practise meditation.
- Spend enough time with loved ones.
- Do at least one relaxing activity every day.
- Do at least one pleasurable activity every day.
- Look for opportunities to laugh!

SELF-MANAGEMENT RESOURCES:

Source: <https://thelupusinitiative.org/patients-caregivers/selfmanagement/mental-and-physical-health-self-management/>

As someone living with lupus, you play a vital role in taking care of and managing your health. There are many things you can do to help improve your lupus-related health problems. Examples include talking with your doctors about your symptoms, working together to develop your treatment plan, reducing stress, eating a nutritious and balanced diet, and incorporating physical activity into your routine.

Everyday Living with Lupus: Be Proactive

Don't be afraid to ask questions. Taking control of your health means taking control of your life. Ask your pharmacist and doctor about the best time to take your medicines, that will help with managing the side effects.

Do not try to hold in all your emotions. Lupus can be overwhelming, so express yourself however you need to. You are not alone in how you feel.

Be kind to yourself by eating healthfully, exercising when you have the energy, and taking time to do things you enjoy.

Do something that makes you happy when you feel the side effects of the medication or symptoms of lupus. It will take your mind off what is going on in your body. Talking with your family, a friend, or a support group during those moments will help too.

You may feel like you have control over your lupus for many week or months and then experience a setback. Do not let that get you down, **refocus and continue taking it one day at a time.**

Self-Managing Your Mental and Physical Health:

It is crucial to remember that there is a connection between emotions and illness. Over time, these stresses and changes can rob patients of the emotional energy that is needed to keep moving. Lack of progress in recovery, or symptoms getting worse can trigger negative thoughts. One may think, "why me? I am never going to get better...". These thoughts can increase anxiety and sadness which can lead to depression.

Feeling bad can often lead to poor eating habits, lack of exercise, isolating yourself. All of these things can worsen one's physical condition. Additionally, it can make it hard to get to doctor's appointments. There are three things people may feel are depression, anxiety, and stress. Below are breakdowns of how one might differentiate between being temporarily upset versus struggling with mental health:

How do we know when we are depressed?

Depression is the most frequently documented psychiatric problem in patients with lupus. Depression has been shown to be a strong predictor of medication non-adherence in lupus. Depression and anxiety are often related to the changes in physical appearance and limitations in physical abilities that come with lupus. Below are symptoms of depression:

- Difficulty concentrating, remembering details and making decisions.
- Fatigue and decreased energy.
- Feelings of guilt, worthlessness and helplessness.
- Feelings of hopelessness.
- Trouble sleeping or sleeping too much.
- Restlessness.
- Loss of interest in activities or hobbies.
- Overeating or appetite loss.
- Persistent sad, anxious or empty feelings, that get in the way of your functioning.

Nervousness versus anxiety:

- Feelings of worriedness or dread.
- Trouble concentrating.
- Feeling tense and jumpy.

- Anticipating the worst.
- Restlessness.
- Watching for signs of danger.
- Feeling like your mind's gone blank.
- Physical symptoms (pounding heart, sweating, stomach or headaches).
- Not just every now and then- really get in the way of your functioning.

The Impact on Caregivers:

Parents and family members of patients with chronic illness also experience stress and mental health issues. Study found that 80% of parents say that their child's condition has affected their work lives, 90% said it affected their mental health, and 70% said it affected their marriage. Caring for a loved one with lupus can reduce the ability of parents to be social and engage in activities outside of the house. Further, high levels of anxiety, overprotection, excessive feelings of responsibility, depression can develop in caregivers.

HOW LUPUS CAN CAUSE BIPOLAR-LIKE SYMPTOMS:

Source: <https://www.verywellmind.com/lupus-bipolar-disorder-379967>

The central nervous system is just one of the targets of the autoimmune response. When it happens, it can manifest with psychiatric symptoms that are strikingly similar to bipolar disorder. While the symptoms of the two disorders overlap, SLE and bipolar are in no way related- SLE does not cause bipolar disorder. However, SLE is sometimes misdiagnosed as bipolar disorder. When this happens, a person may be exposed to unnecessary and inappropriate treatment.

Neuropsychiatric Symptoms of Lupus

When lupus affects the central nervous system, it can cause a variety of symptoms, both neurological and psychiatric. We refer to this condition as neuropsychiatric systemic lupus erythematosus. Symptoms can range from mild to severe and include:

- Headaches
- Memory loss
- Loss of cognitive function
- Tremors, tics, and involuntary movement
- Clumsiness and unsteady gait
- Seizures
- Blurred vision
- Hearing problems
- Speech problems
- Confusion
- Tingling, numbness, burning, and painful nerve sensations
- Stroke

Neuropsychiatric systemic lupus erythematosus (NPSLE) is considered a serious complication that leads to a reduced quality of life and an increase in illness. NPSLE affects about 40 percent of

people with lupus, most frequently manifesting as depression, memory deficits, and general cognitive decline.

Causes: NPSLE is due to a combination of factors including immune dysfunction, hormonal irregularities, vascular inflammation, and direct damage to nervous tissues. Even drug side effects may contribute to the symptoms. The protective layer which surrounds the brain, called the blood brain barrier, can be disrupted by lupus, allowing toxins to penetrate and damage neural tissue.

Diagnosis: Because it is difficult to distinguish between the various causes of NPSLE (including independent psychiatric disorders), there is no gold standard for diagnosis. As such, diagnosis is typically made by exclusion, exploring all other possible causes including infection, coincidental disease, and even drug side effects.

Treatment: The medications used to treat psychiatric and mood disorders may also be used to treat the psychiatric symptoms of lupus. In the event of severe NPSLE, treatment will be focused on the uses of medications that suppress and moderate the autoimmune response.

PSYCHOLOGICAL PROBLEMS WITH LUPUS :

Source: <https://www.lupusuk.org.uk/medical/nurses-guide/psychiatricproblems/>

People living with lupus may develop psychological and psychiatric problems, which affects the brain and can increase fatigue and pain. Unfortunately, psychiatric illnesses are stigmatized, and many doctors and nurses assume that the symptoms are inevitable with the illness. Young women, more commonly, struggle with depression and anxiety; thus, mental illness is usually present in those with lupus.

It is difficult to decipher if symptoms of depression or anxiety are due to mental or physical causes, especially because mental and physical injuries or illness co-exist with one another. Lupus can directly affect the brain and is probably the most feared feature for the patient. These effects may be difficult to quantify, varying by day or by week and making assessment difficult. At its most severe, lupus may cause seizures, strokes, memory loss and psychosis.

Neuropsychiatric symptoms are commonly found even when the biochemical markers of the disease are normal. A history of brief delirium or psychosis, with clouding of consciousness, agitation, fear, visual or auditory hallucinations or paranoid ideas is relatively common. These states are fortunately brief and last only hours or days before subsiding. Occasionally lupus causes an illness which is closer to schizophrenia or bipolar affective disorder. A very small minority of patients go on to develop a dementia syndrome, with loss of recent memory, personality change, speech and co-ordination problems.

The treatment of the psychiatric aspects of lupus clearly depends on the severity of the illness and whether the causes are directly or indirectly attributable to lupus itself or due to co-existent psychiatric problems. Some conditions are brief and self-limiting, requiring only reassurance and brief support. Where there are longer-term emotional problems or recurrent problems that are severe and distressing, referral to a psychiatrist is appropriate.

When assessing patients who are very distressed it is appropriate to enquire sensitively whether they have felt that life was not worth living or demonstrated any example of suicidal

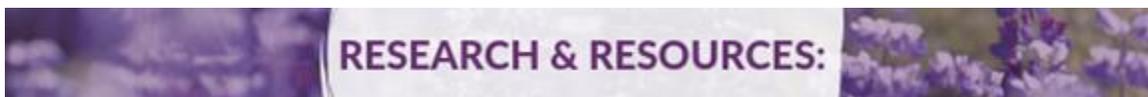
ideation. Counselling or psychotherapies such as cognitive-behaviour therapy or more analytical therapies may be very helpful. Talking therapies such as cognitive behavioural therapy (CBT), motivational interviewing and counselling are proven to be effective in people whose fatigue is not obviously physical in origin.



Source: <https://www.lupusuk.org.uk/medical/nurses-guide/psychiatricproblems/>

"Did you know that more than six in ten people living with lupus say the disease has had a lot of effect on their emotional and mental well-being?"

"According to data from a global online survey nearly 5 000 people with lupus released by the World Lupus Federation for World Lupus Day on May 10, 2019 about one third of respondents also indicated the disease had at least some effect on their emotional status. The 12-question online survey was published in nine languages and was posted on the World Lupus Federation's website from April 15 to April 29, 2019. The survey received 5 073 submissions representing participants from 96 countries."



Are you a good sleeper or do you have difficulties sleeping with lupus? Dr. Da Costa of the Research Institute at McGill University Health Centre and Dr. Fortin of CHU de Québec - Université Laval are conducting a survey to help tailor a behavioral program to help lupus patients improve their sleep. The survey closes on August 30, 2020. Click on the secure link below to participate:

<https://portal.rimuhc.ca/cim/redcap/surveys/?s=ADPLL9KJDJ>

Should the link not work, cut and paste it into your browser.

Êtes-vous un(e) bon(ne) dormeur/dormeuse ou avez-vous des difficultés à dormir avec le lupus? La Dre. Da Costa et le Dr. Fortin, de l'Institut de Recherche du Centre Universitaire de Santé McGill, effectuent un sondage pour aider à adapter un programme comportemental pour aider les patients atteints de lupus à améliorer leur sommeil. Le sondage se termine le 30 août 2020. Cliquez sur le lien sécurisé pour participer:

<https://portal.rimuhc.ca/cim/redcap/surveys/?s=ADPLL9KJDJ>

Si le lien ne fonctionne pas, copiez collez-le dans votre navigateur.

RECIPES:

Vegetarian Stuffed Sweet Potatoes with Hummus

This hearty recipe is loaded with quinoa and your favorite veggies. It's naturally sweet and savory, and as always, everything in it is anti-inflammatory, gluten-free, dairy-free, and soy-free.

Ingredients:

Sweet Potatoes:

- 4 sweet potatoes, large
- 2 tbsp extra virgin olive oil, divided
- ½ cup uncooked quinoa
- 1 cup of water
- Sea salt, to taste
- 1 head of dinosaur flat kale or swiss chard, finely chopped and stems removed
- Juice of 1 large orange
- 1 cup purple cabbage, finely chopped
- 1 tbsp fresh basil, finely chopped
- 2 tsp orange zest
- ½ tsp sea salt
- ¼ tsp pepper

Hummus Sauce:

- 1 cup of plain hummus
- 2 tbsp olive oil
- Warm water, plus more as needed
- Sea salt and pepper, to taste

How to Make It:

Step 1: Preheat oven to 400 degrees F. Prepare a large rimmed baking sheet with parchment paper.

Step 2: Place the sweet potatoes on the prepared baking sheet and rub them with your hands using 1 Tbsp. of the olive oil to ensure the skins are completely coated. Poke holes in them with a fork and roast for 45 -55 minutes, depending on how large your sweet potatoes are. They should be fork tender when done.



Step 3: Meanwhile, cook quinoa according to package directions with 1 cup of water. Add a pinch of sea salt to the water and cook for about 15 minutes or until the quinoa is tender. Remove from the heat, fluff with a fork. Cover and set aside for 10 minutes.

Step 4: In a large bowl, use your hands to massage the kale or swiss chard with the remaining 1 Tbsp. olive oil and orange juice. Season to taste with salt and pepper. Add the cabbage and toss to combine.

Step 5: Add the ½ tsp. sea salt, ¼ tsp. pepper, fresh basil and orange zest to the quinoa and toss to combine.

Step 6: Remove the sweet potatoes from the oven and use a sharp knife to cut them ¾ way through in half lengthwise. Let them sit for 5 minutes to cool while you make the sauce.

Step 7: Place the split open sweet potatoes on a large serving platter. Top with the kale mixture followed by the quinoa mixture and drizzle the sauce on top. Serve immediately.

Sauce: In a medium bowl, combine all the sauce ingredients and mix well to combine until the hummus thins out and resembles a sauce. Start with a small amount of water (such as 2 Tbsp.) and add water as needed because if you use too much water at first while the hummus is still thick, you will have a really runny sauce.

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

Source: <https://thehealthyapple.com/vegetarian-stuffed-sweet-potatoes/>

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 615 Davis Drive Suite 306
Newmarket, ON L3Y 2R2

 Toll Free: 1-800-661-1468
Local: 905-235-1714

 info@lupuscanada.org

 www.lupuscanada.org

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306-615 Davis Drive, Newmarket, ON L3Y 2R2