

## LET'S TALK LUPUS

July Monthly E-Newsletter

LUPUS  
CANADA  
Life Without Lupus



**Lupus Canada would like to wish all Canadians a Happy Canada Day!** The beginning of a new month is a gift, no matter how busy or challenging this month may be, Lupus Canada encourages you to keep moving forward!

Lupus Canada wants to highlight that **International Self-Care Day is on July 24th**. With the summer months being a bit harder to manage for individuals living with lupus, make sure you are putting your needs first! Take advantage of these long days and make the most of this beautiful time of the year.

Thank you to everyone who was able to participate in Lupus Canada's 2021 Informational Survey. This survey was conducted to gather information to advocate and raise awareness for lupus patients across Canada. Together we are making a difference.

Lupus Canada would like recognize and appreciate all the teachers, parents, and students for completing this school year. This past year has created a new set of challenges, to also be living with an autoimmune disease like lupus is an added challenge. Thank you all for the care, commitment, and selflessness everyone has shown.

**DONATE NOW**

your gift makes a difference



### **2021 Lupus Canada Scholarship Program**

Lupus Canada is proud to announce the 2021 Lupus Canada Scholarship recipients. This year we offered six (6) one-time scholarships of \$2,000 CAN to students diagnosed with lupus, who are entering into, or currently enrolled in, a post-secondary educational institution. Thank you to everyone who applied and congratulations to those selected. Each and every Scholarship applicant has a very important story to be told of their journey with lupus. Every month we will feature one of our Scholarship recipients stories.



### ***2021 Lupus Canada Scholarship Recipients***

Sabrina Tran-Jolicoeur  
Koraleigh Ahearn  
Lucie Cvitan  
Elora Grahame  
Morgan Piczak  
Kelsey Bergquist

Congratulations to all our recipients of the 2021 Lupus Canada Scholarships! For more information on the Lupus Canada Scholarship program please visit

<https://lupuscanada.org/news/lupus-canada-scholarship/>.

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### Lupus Canada Summer Student – Claire Luba

Lupus Canada is excited to welcome Claire Luba as our Editorial Assistant. Claire joins the Lupus Canada team for 12 weeks as part of the Canada Summer Jobs program. She will be assisting us with our public awareness and social media initiatives this summer before she heads back to continue her studies at Western University in the Fall. Welcome Claire!

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### Self-Advocacy 2021 Live Webinars

Thank you Melissa Hemphill for joining Lupus Canada at our fifth Self-Advocacy Webinar, 'Nutrition and Lupus' that took place on June 10th. Our guest speaker, Melissa Hemphill, a Holistic Nutritionist discussed Lupus and Nutrition. For a copy of Melissa's presentation, please click [here](#).



Please join us on July 22, 2021 at 7:00 pm (EST) for our next Self-Advocacy Webinar. This month Lupus Canada is joined by Abby Charles who will present "Tips For Being Your Own Best Advocate... Lived Experience With Abby Charles". To register for this webinar please visit [https://zoom.us/webinar/register/WN\\_T0XMx3xxQOu9sK2X4q0jXQ](https://zoom.us/webinar/register/WN_T0XMx3xxQOu9sK2X4q0jXQ).

To watch any of the video recordings of the Self-Advocacy webinars please visit <https://lupuscanada.org/resources/advocacywebinars/>. Do you have an advocacy topic you want to learn more about? Please be sure to email us your ideas to [info@lupuscanada.org](mailto:info@lupuscanada.org).

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### Let's Talk Lupus

Lupus Canada is excited to announce that we are kick-starting our YouTube channel. With educational and informational lupus videos, such as our "Let's Talk Lupus" series, we hope Canadians living with lupus will be able to use these resources to help them manage their lupus.

Let's Talk Lupus, aims to provide the lupus patient and/or caregivers with accurate up to date medical information on topics of interest.

Lupus Canada surveyed lupus patients throughout the country and asked them, "If you could ask a lupus doctor any question, what would that be?" We brought your best queries to medical experts from the CaNIOS, a group of Canadian investigators working together to improve outcomes for lupus patients, who answered them in 12 short informational videos. Lupus Canada's Celebrity Ambassador Patrick McKenna introduces each topic with a prologue at the beginning of the video series.

Be sure to subscribe to YouTube channel by clicking here

<https://www.youtube.com/channel/UCUJmMgmOR7Yarkj-4nVi1nA> .

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### Share Your Story

Have you shared your journey with us yet? Lupus Canada would be honoured to hear about your experience living with lupus. Lupus Canada uses these personal stories about one's diagnostic journey, overcoming daily struggles, or medical journeys to inspire individuals who may be struggling and let them know that they are not alone.

Your story can bring hope to other Canadians living with lupus and help foster a sense of community for lupus patients! To read Isaac Hall's story, Lupus Canada's Youth Ambassador, please click [here](#).

Email us your story at [leanne.mielczarek@lupuscanada.org](mailto:leanne.mielczarek@lupuscanada.org).



LUPUS CANADA WANTS TO HEAR FROM YOU

**SHARE YOUR STORY**

Email your story to [leanne.mielczarek@lupuscanada.org](mailto:leanne.mielczarek@lupuscanada.org)



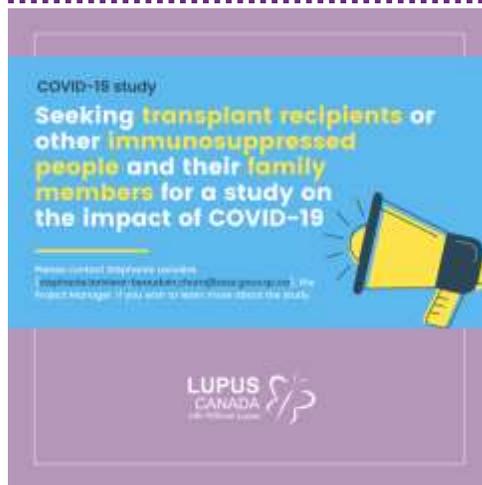
# Great Canadian GIVING CHALLENGE

**Thank you for all your support in June during the Great Canadian Giving Challenge!**

From June 1 – 30, every \$1 donated to Lupus Canada through CanadaHelps gave Lupus Canada a chance to win \$20,000!

All donations raised will be directly impacting Canadians living with lupus and their caregivers. Donations will contribute to our research, awareness, and advocacy initiatives which are all essential to fulfilling our mission of improving the lives of people living with Lupus, and moving towards, "A Life Without Lupus".

Lupus Canada thanks you all for your endless support.



## **Seeking immunosuppressed people and their family members for a study on the impact of COVID-19**

Mélanie Dieudé (CDTRP, CRCHUM), Isabelle Doré (CRCHUM), Sylvain Bédard (Patient, CEPPP), co-investigators of the study "Impact of the COVID-19 pandemic on immunosuppressed people and their relatives" conducted a first data collection during summer 2020 among 137 transplant recipients and their relatives to understand the impact of COVID-19 pandemic on lifestyle behaviours and mental health.

They are now conducting a follow-up among these participants and recruiting new immunosuppressed participants (transplanted or not) and their relatives to investigate changes and current states in mental health and lifestyle behaviours one year after the start of COVID-19 pandemic.

To complete the survey please visit <https://cdtrp.ca/en/seeking-for-transplant-recipients-other-immunosuppressed-people-and-their-family-members-for-a-study-on-the-impact-of-covid-19/>

## National AccessAbility Week (NAAW)

National AccessAbility Week took place from May 30th – June 5th 2021. This year's theme was "Disability Inclusion 2021: Leaving no one behind." To celebrate NAAW, they highlighted the important contributions of persons with disabilities and raising awareness about the work being done to remove barriers to accessibility and promote disability inclusion in Canada.

To mark [National AccessAbility Week](#), Statistics Canada in collaboration with Employment and Social Development Canada, was pleased to unveil the new [Accessibility Data Hub](#).

This new portal provides users with a single point of access for a wide range of data and information related to accessibility. Users can quickly and easily browse various key subtopics – including built environment, design and delivery of programs and services, employment information, communication technology and transportation – and access Statistics Canada's latest data tables, analytical articles and infographics. The Hub also enables users to find external governmental data, as well as information about laws related to accessibility, and will be updated as new data becomes available.

To receive information about our data releases as they are published, consider subscribing for regular updates through [MyStatCan](#).



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## In Memory of Suvi Sunthar

Lupus Canada would like to thank the family and friends of Suvi Sunthar for honouring her memory through a memorial fundraiser. Suvi was diagnosed with lupus at 14, which led to her untimely passing. Her family has shared with us that Suvi had a bubbly personality and despite many of her medical struggles she never let it show and always had a smile on her face. She would always put family first and will be in their hearts forever.

The funds raised will help support Lupus Canada's research initiatives.



## ARTICLES



## LUPUS CARE

### **Your Care Instructions**

Lupus is a long-term disease that can cause inflammation, pain, and tissue damage in your body. It is an autoimmune disease. This means the immune system attacks its own tissues. Lupus may cause problems with your skin, kidneys, heart, lungs, nerves, or blood cells.

This information is about systemic lupus erythematosus (SLE). SLE is the most common and most serious type of lupus. But there are other types of lupus, such as discoid or cutaneous lupus, drug-induced systemic lupus, and neonatal lupus.

When you have lupus symptoms, you are having flares or relapses. When your symptoms get better, you are in remission. Lupus may get worse very quickly. There is no way to tell when a flare will happen or how bad it will be. When you have a lupus flare, you may have new symptoms as well as symptoms you have had in the past.

Learn your body's signs of a flare, such as joint pain, a rash, a fever, or being more tired. When you see any of these signs, take steps to control your symptoms.

Follow-up care is a key part of your treatment and safety. Be sure to make and go to all appointments, and call your doctor or nurse call line if you are having problems. It's also a good idea to know your test results and keep a list of the medicines you take.

*How can you care for yourself at home?*

- Reduce stress and tiredness
- Keep your daily schedule as simple as possible.
- Keep your list of things to do as short as you can.
- Exercise regularly. A daily walk or swim, for example, can lower stress, clear your head, improve your mood, and help fight tiredness.
- Use meditation, yoga, or guided imagery to relax.

- Get plenty of rest. Some people with lupus need up to 12 hours of sleep every night.
- Pace yourself. Do not do too many activities.
- Ask others for help. Do not try to do everything yourself.
- Take short breaks from your usual activities. Think about cutting down on work hours when your symptoms are severe.
- If you think that depression or anxiety is making you feel more tired, talk to your doctor, a mental health professional, or both.

#### *Take care of your skin*

- Ask your doctor about the use of corticosteroid creams for skin symptoms. If you are bothered by the way a lupus rash looks on your face or if you have scars from lupus, you can try makeup, such as Covermark, to cover the rash or scars.
- Stay out of the sun, especially when the sun's rays are the strongest, usually between 11 a.m. and 3 p.m. If you must be in the sun, cover your arms and legs, and wear a hat. Make sure to use a broad-spectrum sunscreen that has a sun protection factor (SPF) of 50 or higher. Put more sunscreen on after swimming, sweating, or towelling off.

#### *Practice good self-care*

- Learn more about lupus and how to take care of yourself.
- Take your medicines exactly as prescribed. Call your doctor or nurse call line if you have any problems with your medicine.
- Do not smoke. If you need help quitting, talk to your doctor about stop-smoking programs and medicines. These can increase your chances of quitting for good.
- Eat a healthy, balanced diet. A balanced diet includes whole grains, dairy, fruits and vegetables, and protein. Eat a variety of foods from each of those groups so you get all the nutrients you need.
- Avoid other people who are sick with colds or influenza (flu). These illnesses can cause lupus flares. Talk to your doctor about flu shots and pneumococcal vaccinations. If you do get sick or think you are getting an infection, talk with your doctor so you can treat your symptoms right away.
- Brush and floss your teeth each day. See your dentist two times a year.

- Get regular eye examinations.
- Build a support system of family, friends, and health professionals.

Source: <https://myhealth.alberta.ca/Health/aftercareinformation/pages/conditions.aspx?>

## WHAT IS SELF-CARE?



*"Promise me you'll always remember:  
you're braver than you believe, and  
stronger than you seem, and smarter  
than you think,"*

A. A. MILNE



Many of us have so many responsibilities in life that we forget to take care of our personal needs. While it is hard to prioritize something like taking time to relax when you have so many other things on your to-do list, good self-care is a key to improved mood and reduced anxiety. It's also a key to a good relationship with oneself and others.

### What is Self-Care?

Self-care is any activity that we do consciously in order to take care of our mental, emotional, and physical health. It is, in essence, the mindful taking time to pay attention to yourself in a way that ensures that you are

being cared for by you.

Self-care is often about setting yourself up to succeed in your life, and sometimes that means admitting that you can't do everything all alone. This is where you need to accept help from others. Creating and maintaining connection with those around you (when possible) is a bonus example of self-care in action.

### What It Isn't?

Knowing what self-care is not might be even more important. It is not something that we force ourselves to do and don't really enjoy doing it. Taking care of our own needs can sometimes be confused with self-indulgence or selfishness, but it is neither of those. In order to be able to help others, we need to be energized and feel positive. If we are not making this practice a daily ritual, then we are not being the best we can for ourselves or for anyone else. It's not about only 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.

Self-care is not about pleasing everyone. So many of us might try to do this. Sometimes we do this without even realizing it and at the expense of our own health and happiness. It is a common mistake for caretakers to be too focused on the needs of others at the expense of attending to their own needs. Not only is overextending yourself for others not helpful to you, it can be bad for all parties in the end. Exhaustion can lead to mistakes in the short term. In the long-term the over-extending can have life-altering health complications.

Proper self care isn't about jumping from one fad diet to the next or obsessively working out in an effort to create a chiseled body either. Exercise as self-care works when it's about feeling good, healthy, and self-confident, not when it's about heading to the gym with the sole intension of burning off the four donuts you treated yourself to at work because you want to be bikini-ready by the weekend.

### **Why Self-Care is Important?**

We are less able to handle the stresses that come our way when we're already depleted by physical and emotional exhaustion. Or, putting it in a more positive way, we are more resilient and more able to handle life's stress when we are feeling our best both physically and emotionally. Thus, taking time out to maintain self-care has several benefits: affecting your physical health, emotional health, and makes you a better caregiver.

Self-care is important to maintain a healthy relationship with yourself, sometimes called self-love. It produces positive feelings, which improves confidence and self-esteem too.

Self-care is important for your family and friends too. They learn from you, so setting functional boundaries to take care of yourself shows them that they too need to put themselves first and not overextend or overwork.

### **How to Start?**

Although self-care means different things to different people, there are three golden rules to be followed.

Stick to the basics. Over time you will find your rhythm and routine. You will be able to implement more and identify more particular forms of self-care that works for you.

Self-care needs to be something you actively plan, rather than something that just happens. It is an active choice and you must treat it as such. Add certain activities to your calendar, announce your plan to others in order to increase your commitment, and actively look for opportunity to

practice self-care.

If you don't see something as self-care or don't do something in order to take care of yourself, it won't work as such. Be aware of what you do, why you do it, how it feels, and what the outcomes are.

### **As You Need Self-Care, Others Need It Too!**

It is important to make sure you take good care of your body, mind, and soul every day, not just when you get sick. Practicing self-care isn't always easy and it can be challenging to get started. Fortunately, there are many things you can do to engage in self-care.

No matter which practices you choose, the goal is to figure out which self-care strategies work best for you, learn how to use these strategies, and implement them in your regular routine so you can boost your well-being not only today but forever. Support the well-being of others by sharing this article. Help others understand the importance of self-care and how it can impact health.

Source: <https://progressivehousing.net/self-care/what-is-self-care/>

## LUPUS REMISSION GUILT

### **Introduction**

Living with chronic illness – including systemic lupus erythematosus– can cause an individual to experience a gamut of emotions. At times, they may feel anxious or fear about the unknown, joyful when having enough spoons to get through the day or sadness if school or work is missed because of health. No one is ever really fully prepared for the feelings being ill can bring – the emotional side of illness can be as complex as experiencing the physical symptoms themselves. There may be times when an individual's resiliency and resolve may be stronger some days than others and therefore, coping with the same issue can cause completely difference emotions.

When an individual with lupus enters remission, however, the same myriad of emotions may still exist. While the focus is usually on improved physical health and the relief of loved ones, an individual's emotional well-being may be taken for granted. Meaning, if they are physically well, they should be mentally well. An individual's support system may even tell their loved one that they should feel lucky to be in remission and should be happy to be (mostly) healthy again. The individual themselves may think that they should feel relieved to be healthy and out of danger, but for some reason they cannot. They may actually feel guilty for not only being in remission, but for not being able to emotionally feel better, too.

## What is Lupus Remission Guilt?

Remission guilt is a real emotion. Originally coined in 1943 by Drs. Stanley Cobb and Erich Lindemann as “survivor’s guilt,” an individual may experience this nature of guilt when they survive a traumatic experience such as recovering from long-term illness, surviving a natural disaster or even war. An individual who is fortunate enough to get through these events and survive may ask themselves, “Why me?” or “Why not her?” They may also begin to question their own worthiness or even willingness to feel better. Attaining remission can mean a huge lifestyle change that may be difficult to emotionally navigate after feeling so bad for so long. It may also mean feeling like they no longer belong or will no longer be accepted by those still struggling with managing lupus symptoms. These emotions can be hard to juggle and balance in a healthy way.

*Angela Long explains some of the emotions that may be experienced with remission (or survivor’s) guilt:*

- *Empathy:* Feelings of empathy towards others may increase as one becomes more aware of others’ challenges when they are no longer so focused on their own health. An individual may experience a range of emotion from sadness for others to hope.
- *Sadness:* The sadness experienced through empathy for others needs to be released. Long recommends using the shower as a place to release those tears because a shower can be a safe and soothing place with no one around to hear or interrupt. Long also suggests, however, that after the tears are released, the individual listen to upbeat music or participate in some activity – even if it is just completing routine tasks – in order to stay upbeat and focused on something else.
- *Anger:* With anger comes a lot of energy that needs to be released in a healthy way. This tension can be dealt with by identifying triggers and working on how to cope with them ... even the occasional healthy venting to someone who is supportive might help release that tension.
- *Grief:* An individual who is now in remission may not only grieve those who are still very sick or who have not survived, but ironically they may also grieve their past life when their lupus activity was high and life was different, but manageable. Grief can include feelings of lethargy, sadness, irritability and changes in sleeping habits. Long recommends patience as the best thing that can work over time to alleviate feelings of grief.
- *Anxiety:* Destructive, anxious thoughts include over-generalizing, catastrophizing, assuming, dwelling on the negative or comparing oneself to others. A therapist can help

an individual develop coping skills to manage anxious feelings and thoughts. Activities such as exercise, yoga, mindfulness meditation or even journaling can also help manage anxiety.

- *Pressure:* An individual in remission may feel pressure (often placed on themselves) to help others and give back. While this is a great way to stay engaged and active and share experience and knowledge, an individual needs to honor how they are feeling and not be afraid to still ask for help from others when they need it, too.

### **Shame vs. Guilt in Lupus Remission**

Now, something about shame and guilt – two emotional experiences that have a good deal in common and sometimes experienced together. It is not unusual for individuals feeling remission guilt to also experience shame, and it is important to understand their differences in order to better understand and deal with each.

Guilt is felt when an individual acknowledges to themselves (correctly or incorrectly) that they have done something wrong. It is a very internalized feeling because the individual experiencing the guilt does not necessarily worry about how others perceive them – they only concerned about their own knowledge of their guilt or innocence. When an individual feels guilty, their own conscience tells them that they have done something wrong and they feel remorseful about it – even if no one else blames them. An individual experiencing remission guilt, however, is experiencing unhealthy guilt because they believe they have somehow wronged others who are still experiencing symptoms by becoming well. No matter how many times others may celebrate the individual's remission, they may still feel bad about it.

Joaquín Selva, Bc.S. explains that shame is “[regretting] some aspect of who [an individual is] as a person.” Yet, shame is more externally focused than guilt. Shame occurs when an individual worries about how they appear to others, and so it has more of a social context. Shaming requires others to be the source of judgment and blame for the individual who feels it. That person may feel others are constantly judging them because of a perceived fault. An individual with lupus may be ashamed of their chronic illness because of how it will look to those who are healthy. While someone in remission may also feel ashamed because their perception of how those not in remission might feel about them.

*Guilt:* “I feel badly because I don’t deserve to feel healthy again.”

*Shame:* “I feel badly because others think I don’t deserve to feel this way.”

### **Managing Lupus Remission Guilt**

Leonard recommends the following for managing remission or survivor's guilt:

*Accept and allow the feelings.*

It is important for the individual to allow themselves time to feel what they are going to feel and remind themselves that they can handle it. There are no “shoulds” when it comes to human emotion. Emotion is healthy. Denying emotion, however, is unhealthy and can be detrimental to overall well-being.

*Connect with others.*

One of the best things an individual can do is to find others with their same experiences. It is important to find and attend support group meetings with individuals who have lupus whether or not they are physically feeling better. Not only will others be encouraged by their story, but the individual themselves may feel useful and a source of hope. Often, the knee-jerk reaction is to stop attending support groups because an individual feels better and assume they do not belong anymore because they are in remission. This is actually the best time to attend. There may be opportunities to mentor or advocate for other support group members or volunteer for the organization hosting the group.

*Use mindfulness techniques.*

Breathing exercises, acknowledging thoughts, focusing on surroundings and the sensations the environment causes (touching, tasting, smelling, hearing and seeing), or even just meditating quietly for a moment or two can be ways for an individual to ground themselves. Yoga can be a great way to more “actively” meditate as both movement and breath need to be aligned.

*Practice self-care.*

Get a massage, rest or nap, eat healthy food or exercise can be ways to practice self-care. Even journaling, listening to music or watching a favorite movie can provide respite from overwhelming feelings of guilt. An individual should also make sure to start any new activity with care and pace themselves and not force things when they really just may want to or need to chill out.

*Do something good for others.*

As mentioned earlier, volunteering or mentoring may be great ways to get involved and do something good inside or even outside of the lupus community. Advocating for others with lupus and educating others can also be a great way to stay involved and “pay it forward.” Offering services to other organizations may be a great way to broaden horizons, expand social circles and balance other interesting aspects of life with lupus.

*Seek professional help.*

Talking openly and honestly with a trusted healthcare practitioner can open the door for seeking emotional help – they can help an individual find appropriate therapists to manage emotional health. Cognitive behavioral therapy is a great way to openly and safely discuss how an individual is feeling. Therapists can also provide coping strategies in order to manage guilt, PTSD or any range of feelings and individual may be experiencing. Sometimes it just feels good to talk to an unbiased third-party about what an individual is experiencing.

*In Conclusion*

Remission means change, and change can be stressful – even a change that you have spent years hoping for! While remission guilt is common, it does not mean you have to live with it day in and day out. No one has to make it their new “normal.” Everyone experiences lupus differently and everyone can experience remission differently. That fact alone should remove some of the pressure that someone feels to react to remission a certain way. Identifying the symptoms of guilt and learning how to manage those complex feelings may be some of the most important skills to develop in the journey from lupus to a healthier life.

Source: <https://kaleidoscopefightinglupus.org/lupus-remission-quilt/#second-paragraph>

## RECIPES



### Vegan Sweet Potato Casserole

PREPARATION: 15MIN  
COOKING: 90MIN  
SERVES:12

#### INGREDIENTS

- For the Base:
- 3 pounds sweet potatoes (scrubbed)
- 1/3 cup apple juice concentrate
- 1/4 cup maple syrup
- 2 teaspoons cinnamon
- 1 teaspoon fresh nutmeg
- 1 tablespoon vanilla extract
- Dash of salt

#### Topping:

- 1/2 cup gluten free oats
- 1 cup chopped nuts (walnuts or pecans)
- 1/4 cup coconut oil
- 1/4 cup maple syrup
- 1 teaspoon cinnamon
- 1/2 teaspoon nutmeg

#### DIRECTIONS

Roast sweet potatoes at 400 degrees for about 45 minutes, or until fork tender. Cool slightly. And lower temperature to 350 degrees.

Remove skin of sweet potatoes (simply by peeling off skin with fingers) and place the pulp into a large blender or food processor (or use a hand/stand mixer).

Add the remaining ingredients for the base and puree/mix until smooth and then transfer to a 2 quart casserole dish.

Combine the oats, nuts, coconut oil, maple syrup, cinnamon, and nutmeg together until crumbly. Sprinkle over the casserole. Bake at 350 for 45 minutes or until topping is golden brown.

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

Source: <https://amindfullmom.com/healthified-sweet-potato-casserole-gluten-free-vegan/>

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