



## LET'S TALK LUPUS

April Monthly E-Newsletter

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CANADA  
Life Without Lupus



This month we recognize **World Health Day on April 7th**, which allows individuals and charities to promote global health. Whether it is mental health, childcare, or health services, we must remember to think about how these all interconnect and impact our overall health.

Lupus Canada is thrilled to announce that next month is **Lupus Awareness Month**. This month allows advocates to recognize **World Lupus Day on May 10th** and spread awareness through **Put on Purple Day on May 21st**. These dates are important to supporting and advocating for those who live with lupus. If you would like to support individuals living with lupus, please consider donating to Lupus Canada with a one-time, in-honour, in-memory or monthly donation. No matter how big or small the donation, it will make a difference in the lives of many Canadians. Visit <https://lupuscanada.org/get-involved/ways-to-donate/> for more information on how you can help!

**DONATE NOW**

your gift makes a difference



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## Advocacy 2021 Live Webinars

Lupus Canada is pleased to share that our second **Advocacy Webinar, 'Managing Your Finances'**, took place on March 18th! If you missed the either of the first two webinars please visit <https://www.youtube.com/playlist?list=PLqd5uEPIER8Pkv7miOFH1YMLxZRrPe7Iu> for the recorded versions.

This month we are excited to present **Mental Health and Lupus as our third Advocacy Webinar**. Janice LeBlanc, a Registered Psychotherapist will address topics such as:

- How lupus can impact mental health
- What help and/or programs are available
- How would a lupus patient advocate for themselves or a loved one living with lupus to ensure to get the help they require
- Coping strategies – how to help yourself

For more information on upcoming webinars please visit <https://lupuscanada.org/get-involved/advocacywebinars/>. If you have an advocacy topic you want to learn more about please email us your ideas to [info@lupuscanada.org](mailto:info@lupuscanada.org).

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## Lupus Canada 2021 Scholarship Program

Lupus Canada is pleased to announce the 2021 Scholarship program! Lupus Canada created the Scholarship program to help students living with lupus to succeed in attaining a post-secondary education. Through the financial support of the Lupus Canada Scholarship, we intend to recognize and raise awareness of the achievement of students living with lupus who have taken a positive and ambitious outlook in achieving their academic goals.

We will be offering six (6) one-time scholarships of \$2,000 CAD to students diagnosed with lupus, who are entering into, or currently enrolled in, a post-secondary educational institution. We are honoured this year to announce that one of the Scholarships will be named in Memory of Debra Camilleri for her 15 years of volunteer work as the President of the Kelowna Lupus Support Group in British Columbia. For more information on the Scholarship program and how to apply please visit [lupuscanada.org/news/lupus-canada-scholarship](https://lupuscanada.org/news/lupus-canada-scholarship).

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## Put on Purple T-Shirts Now On Sale!

Wear your favorite purple items on May 21st to raise lupus awareness and encourage others to donate!

Whether it's a purple shirt, hat, sunglasses or more, Go Purple To End Lupus and share why you're wearing purple and support efforts to advance lupus research by either raising funds or making a donation. Tell your friends and family how they can donate and get involved. As a community lets work together to find a cure for this disease alone.

You can be a part of the growing number of individuals, communities, media and celebrities that are making a difference this Lupus Awareness Month in the fight to end the brutal impact of this disease.

For more information please visit <https://www.lupus.org/lupus-awareness-month/put-on-purple>.

**Get your POP t-shirt in time for Put on Purple day in May! To order yours please visit [www.lupuscanada.org](http://www.lupuscanada.org) or call 1 800 661 1468.**

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**#LUPUSCANADACARES**

*"Hope is in the strength we have to carry on even through the toughest of days. Together we will weather this storm and come out stronger. Cheers to 2021, a year of hope and gratitude."*

**LEANNE MIELCZAREK**  
EXECUTIVE DIRECTOR, LUPUS CANADA

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*"In spite of the unknown and the uncertainty we have been facing, tomorrow is full of hope and possibilities. Together, through kindness, compassion and understanding, we will accomplish great things."*

**CORA NOVACUT-LEE**  
MANAGER, DONOR RELATIONS-SPECIAL PROGRAMS, LUPUS CANADA

**#LUPUSCANADACARES**

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**#LUPUSCANADACARES**

*"Hope is a choice - as we tread cautiously into the new year, never underestimate yourself because the hope that is in each one of us can bring a perspective toward a brighter tomorrow!"*

**ISAAC HALL**  
LUPUS CANADA YOUTH AMBASSADOR

## Lupus Canada Campaign Of Hope!

For all Canadians and everyone across the globe this past year has been very challenging. Especially for someone living with lupus it has been especially challenging to stay positive and hopeful. In 2021 Lupus Canada wants to remind everyone that there is hope for a better year. Through our #LupusCanadaCares campaign we will share messages of hope from a variety of folks across Canada.

Lupus Canada looks forward to when we can have in-person events and fundraisers again. But, until then we invite you to join us in this campaign by sharing your own messages of hope for 2021. Take a picture of something that brings you happiness, caption it with your message of hope, and tag Lupus Canada!

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## Lupus Canada Light Illumination List 2021

LOCATION	DATES
<b>ALBERTA</b>	
Calgary Tower, Calgary, AB	Monday May 10th, 2021
High Level Bridge, Edmonton, AB	Friday May 21st, 2021
Lethbridge City Hall, Lethbridge, AB	Monday May 10th, 2021
Canopy at Shell Place, Fort McMurray, AB	Monday May 10th, 2021
<b>BRITISH COLUMBIA</b>	
BC Place, Vancouver, BC	Monday May 10th, 2021
Port Coquitlam City Hall, Port Coquitlam, BC	Monday May 10th, 2021
Sails of Light, Vancouver, BC	Monday May 10th, 2021
<b>PEI</b>	
City Hall, Charlottes Town, PEI	Monday May 10th, 2021
<b>NOVA SCOTIA</b>	
Halifax City Hall, Halifax, NS	Monday May 10th, 2021
<b>ONTARIO</b>	
3D TORONTO Sign, Toronto, ON	Friday May 21st, 2021
Brant Street Pier, Burlington, ON	Monday May 10th, 2021
CN Tower, Toronto, ON	Monday May 10th, 2021
Niagara Falls, Niagara Falls, ON	Monday May 10th, 2021
Port Credit Lighthouse, Mississauga, ON	Monday May 10th, 2021
Kingston City Hall, Kingston, ON	Monday May 10th, 2021

## Get Involved in Lupus Awareness Month!

Lupus Canada is challenging you this Lupus Awareness Month to reach out to your local governments and landmarks to recognize World Lupus Day. Lupus Canada is thrilled to announce the landmarks are already approved to be illuminated in purple for World Lupus Day on May 10th and Put on Purple Day on May 21st, please see the list for more information! If you are able to reach out to your local governments and celebrate Lupus Awareness Month we ask you to share this with us by taking a picture, posting on your social media, and tagging @LupusCanada!

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## Lupus Canada Campaign Of Hope T-Shirts!

We are thrilled to announce that the launch of the Lupus Canada Campaign of Hope has been a success! Thank you to everyone who has so far purchased a t-shirt and shown your support. We believe that hope is the strength we have to carry on even during the toughest of days. We are excited to see everyone wearing these t-shirts, especially during Lupus Awareness Month. For more information on how to purchase your Hope T-shirts please visit <https://lupuscanada.org/merchandise/hope-t-shirt/>.

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## What's Happening At Lupus Canada?

We would like to thank Tanya Carlton for her years of service as Lupus Canada's President. Tanya donated her time and expertise to the organization for more than 6 years. During Tanya's tenure as President with Lupus Canada we have seen significant growth in awareness for this debilitating disease. Tanya's passion to help others impacted by lupus is shown by her ongoing commitment to the Lupus Canada Scholarship program. Though Tanya has decided to step away, she won't be too far away as she will continue to represent the organization in the role of Past President.

We are pleased to welcome Malcolm Gilroy to the role of President. Malcolm brings many years of experience with the organization as he has previously held both the roles of Vice President and most recently the role of Treasurer. Malcolm's dedication to our mission and vision of improving the lives of Canadians living with lupus through research, advocacy, public awareness and education is unparalleled.

We would like to also thank our team of very dedicated and passionate Board of Directors. Board service is one of the most challenging volunteer roles. A very special welcome to our newest Board members, Mark, Brenna and Michelle we are honoured to have you on our team. For more information on our team of Directors please visit <https://lupuscanada.org/about-us/our-team/>.



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### Spotlight on Lupus Canada's Board Member - Michelle Gazze

#### *Winnipeg women offer advice, encouragement to their younger selves through letters*

Advice aimed at encouraging young women and girls who are disproportionately impacted by the pandemic.

The realities of everyday life during the COVID-19 pandemic have been deeply felt by women.

While the unemployment rate for women in Manitoba last month dropped to 7.3 per cent — from 9.4 per cent in January 2021 — there are still gaps between how men and women are experiencing job loss and household pressures.

CBC Manitoba reached out to female community leaders in our province earlier this month, on International Women's Day, and asked them to write letters that offered advice and encouragement to their younger selves.

Sharing these letters on social media was a way for women to help others who might be struggling to cope during COVID-19.

**Michelle Gazze: Your path is going to look different**

Michelle Gazze is a community-driven leader. From career development to communications, she has over 10 years of experience leading community engagement initiatives for non-profit, private and public organizations.

Born in Winnipeg and representing deep Guyanese roots, she is passionate about maintaining her self-identity while creating environments that support inclusivity for new Canadians through her volunteer work with the Immigrant and Refugee Community Organization of Manitoba, the Rising Stars Foundation, and as a board member with Lupus Canada.

For more information please visit <https://www.cbc.ca/news/canada/manitoba/winnipeg-women-letters-to-younger-selves-1.5954963>.



### **Healthy minds live in healthy bodies**

Mental health and physical health have a lot in common. Both benefit from basic and regular maintenance. Nutrition and exercise are the basic maintenance for both a healthy mind and a healthy body.

While diet and exercise are often thought of as tools of physical health, research has shown that these factors have an impact on how we feel and how well we function mentally and emotionally, as well as physically. Many of the symptoms associated with deterioration in mental health – including fatigue, lack of energy, poor concentration, anxiety and poor body image – benefit from exercise and a healthy diet.

Diet and exercise are also crucial to the prevention and management of many chronic diseases, such as diabetes, obesity, and cardiovascular disease, among many others. Maintaining physical health can help avoid not only physical illness, but it can also support resiliency in your mental health. Conversely, poor physical health can lead to increased vulnerability for mental illnesses, such as depression.

### **Diet and nutrition**

It makes sense that a nutritious diet helps keep you healthy both physically and mentally. Good nutrition helps the body maintain a healthy weight, manage stress, and fuels the physical activity that is part of a healthy lifestyle.

The brain, like any other organ, needs the right nutrients to function well. And many brain functions – from regulating hormones to falling asleep to concentrating – can affect mood.

All activities of the brain, those you are aware of and those you aren't, involve a series of chemical processes and impulses. The raw materials for those neurological processes come from nutrients: proteins, complex carbohydrates, the right fats, and vitamins and minerals are all required to keep the brain healthy.

Studies have linked the Mediterranean diet, which is rich in fruit, vegetables, whole grains, fish and healthy fats, to decreased risk of depression. Other research has suggested a link

between deteriorating diets in western countries – marked by higher intake of processed foods high in fat, sugar and sodium – and increased incidence of mental illness.

Research has shown that some foods appear to be linked to brain functions. For example, antioxidants may help prevent the memory problems associated with cell damage from chemicals called free radicals. Omega-3 fatty acids found in fish and fish oil – particularly docosahexaenoic acid (DHA), the most abundant omega-3 fatty acid in the brain – have been linked to improved cognitive function.

There is debate about whether there are direct links between specific nutrients and mood. However, it does appear that all of the foods thought to be helpful – which include B vitamins, folic acid, omega-3 fatty acids, and minerals such as magnesium and zinc – are all found in healthy, balanced diets.

Certain mental illnesses can impact nutrition. For example, it is not uncommon for people who are depressed to notice changes in how much they eat – either eating significantly more or less. Others may notice an increase in craving certain foods high in sugar or simple carbohydrates. These foods might make you feel better when you first eat them, but can actually exacerbate your depression because they lead to a “sugar crash.” Certain medications used to treat mental illness can affect your diet, causing weight gain or nausea. The relationship between mental health and diet is complex – they are both impacted by and impact each other.

### **Fitness and exercise**

All the physical aspects of exercise that benefit the body (such as increased circulation, improved metabolism, and the body’s ability to use oxygen more efficiently) also benefit the brain and all of the neurological functions it performs.

Exercise is an effective tool for managing stress, as well as symptoms that stem from stress including worry, irritability and sleep problems. Studies have shown that aerobic exercise can help alleviate anxiety, and there is a wealth of research pointing to the close link between exercise and mood. In fact, one of the most important lifestyle modifications that people at risk for depression can make is to exercise regularly.

Studies have shown that exercise releases serotonin, the same neurotransmitter in the brain that is targeted by many antidepressants. It also releases endorphins, the neurotransmitters that help alleviate pain and reduce stress. These are the same chemicals responsible for the euphoria known as “runner’s high.”

The effects of exercise on the immune system boost both mental and physical fitness. Regular exercise helps boost white blood cells and can help fight off infection. It can also help reduce levels of cytokines, a type of immune system chemical that may aggravate depression.

In addition to its physical benefits, exercise has psychological benefits as well. It can build confidence, help people set and meet goals, and may help prevent isolation by getting people into the community.

### **Sleep**

The benefits of a good night’s sleep include being alert and refreshed, able to concentrate

and perform complex physical and mental tasks. It also helps you stay healthy both mentally and physically, and is a key element in managing stress.

Sleep is important for brain function, and is closely linked to neurotransmitters associated with mood, such as serotonin and melatonin.

The effects of poor sleep on mood and emotional state are often immediate. For a magnified glimpse at some of these direct effects, have a look at an exhausted child. When toddlers miss their naps, they can be emotional, irritable, irrational, and less able to concentrate or do things they normally can. The effects aren't much different in grown-ups! In addition to being drowsy and irritable, adults who don't get enough sleep also don't function as well physically, have impaired memory and attention spans, and find it difficult to concentrate.

Lack of sleep doesn't just make you sleepy, it makes the body and the mind function poorly. Sleep is when the body does important repair and maintenance work. Tissue repair and cell regeneration get underway while we rest, and the brain appears to use this time to regulate important chemicals such as human growth hormone. This hormone is not only responsible for making us grow from children to adults, but also for the upkeep and repair of all of our tissues and organs throughout our lives.

Sleep deprivation puts the body under stress, which makes it difficult for the immune system to function properly. This makes the body more vulnerable to colds and flu and other infections. In addition, a sleep-deprived immune system is also more likely to trigger the type of inflammatory responses that are implicated in the development of many serious diseases, including high blood pressure and cardiovascular disease.

Not getting enough sleep can take its toll physically, mentally, emotionally and professionally. It can affect work, family, relationships and both physical and mental health.

### **Stress management**

There's no avoiding stress. Everyone's life has some pressures and challenges. Sometimes these are exciting and positive things – like getting a promotion or planning a wedding or having a baby. Others are unexpected or sad, such as an illness or job loss or the death of a loved one. Sometimes stress comes from minor, day-to-day things.

Since there's no avoiding stress, it's important to have healthy ways to manage it.

Stress contributes to both physical and mental illness. In the body, stress can cause high blood pressure, upset stomach, aches and pains, and insomnia. It can bring conflict into family life and personal and professional relationships. In the mind, it can lead to anxiety, irritability, and negative emotions. In fact, stress has many symptoms in common with mental illnesses, such as causing sleep problems, difficulty concentrating, irritability, and appetite changes.

One of the dangers of stress is its connection with unhealthy coping mechanisms. People who are busy and stressed may neglect to eat well. It's quicker to pick up takeout – or skip a meal altogether – than to do the shopping and prepare something nutritious. Stressed people may be more likely to skip workouts or fitness activities, stay up late to meet deadlines, and may smoke more, drink more alcohol or use more drugs.



It's unfortunate that the things that stressed people tend to neglect are the very things that help people cope better with stress. A healthy diet, regular exercise and sufficient sleep help your body and mind manage stress. Other tips that may help manage stress include:

Understand your stress: being aware of what events and situations are contributing to your stress levels can help you find ways to prevent and manage it.

Learn how to unwind: think of relaxation as a skill that you can develop. Learn a technique such as deep breathing or visualization. Some people find activities such as yoga, tai chi, or meditation very helpful.

Consider learning about stress management by taking a workshop or reading about it. Ask for recommendations from your doctor, a health-care provider or your human resources department at work.

Many people find that balancing their roles and responsibilities can help keep stress from taking over. This often means thinking about what's important to you, making priorities, knowing your limits, and respecting those limits by learning to say no to tasks and responsibilities that may not fit into your priorities.

Make your own well-being a priority: eat well, stay active, sleep and nurture healthy relationships.

Source: <https://www.womenshealthmatters.ca/health-centres/mental-health/mental-health-and-well-being/healthy-minds-live-in-healthy-bodies/>

## LIVING A BALANCED LIFE WITH LUPUS

A lupus diagnosis can leave you reeling. Initially, it may be a relief to have a name for the fatigue and pain you have, but you may be wondering what happens next. Chronic diseases need a lifetime of care.

It will impact not only your health but your lifestyle as well. Lupus can create physical changes, mental health challenges, and affect your personal relationships. It may be frustrating to feel limits and setbacks, but know that there is a lot you can do to manage lupus.

### **Flare-Ups**

Lupus is a disease marked by periods of remission with no symptoms, offset by periods of symptom flare-ups. A flare-up is an unwelcome and often frustrating event. Symptoms will vary from person to person. But for each individual, the flare-ups may be similar each time. They may include:

- Persistent fatigue, weakness
- Loss of appetite, recurring abdominal pain, nausea or vomiting
- Unusual headaches, aching all over
- Painful and swollen joints, increased swelling of the feet and legs, stiff joints in the morning

- Unexplained skin rash, hives, sores on skin, increasing hair loss, sores on roof of the mouth
- Fever
- Involuntary weight loss
- Recurring nosebleeds, coughing up blood
- Shortness of breath, pain in chest when breathing
- Blood in urine
- Neuropsychiatric symptoms

You will most likely be able to recognize signs that a flare-up is on the way and even understand the triggers. Triggers can be from poor diet, lack of sleep, too much stress, and exposure to colds, the flu or sunlight. You cannot completely control all flare-ups, but you can better understand them. Keep a journal when flare-ups start. Track the symptoms and triggers. The more you know about the flare-ups the better you can decrease their intensity or frequency.

### **Physical Disabilities**

Most people with lupus will have joint and muscle pain. At times the pain may be disabling. People with lupus are also more prone to osteoporosis and the bone fractures associated with it. Some of the bone damage may be due to medications. Follow your doctor's instructions for medication and supplements to decrease bone loss as much as possible.

It may seem like rest is best for joints and bone problems, but this can make the situation worse. Keeping physically active can help decrease the strain on joints and muscles and make bones stronger. It is best to take into account your current symptoms when developing an activity program. Fortunately, there are many ways to be active.

- **Water activities**, such as water aerobics or swimming, low-impact devices, such as cushioned treadmills or elliptical machines, and proper footwear can help take pressure off of joints while giving you a good workout. An exercise specialist can help you find appropriate activities.
- **Focus on a progressive routine** by beginning at a low intensity. Gradually work your way up. Attacking a program that is too intense can backfire on you.
- You may need to create a program that allows for rest periods.
- **Develop a program** that includes both cardiovascular and strength activities .

Back off of your routine during flare-ups. Work with physical or occupational therapists to address problems that are interfering with your everyday life.

### **Skin Changes**

Skin rashes and lesions are a common symptom of lupus. In most cases, it is due to the disease itself, but medications may also make your skin more vulnerable. Precautions need to be made to protect your skin. For optimal skin health:

- **Wear sunscreen** with SPF 30 or higher that blocks UVA and UVB rays. Sunlight is a trigger for lupus flares.
- **Limit outdoor activity** during peak hours between 10am-4pm
- **Choose protective clothing**: wide-brimmed hats, long sleeves, UV-protective clothing.
- **Avoid tanning beds.**

- **Make-up is fine**, but choose hypoallergenic brands. Look for makeup that is also UV-protectant.

Sometimes rashes cannot be prevented. Skin changes can have an emotional impact because of the highly visible nature. If you feel that your rashes or sores are interfering with your life, talk to your doctor.

### **Mental Health**

It is common for anyone managing a chronic illness to have bouts of depression. In addition, some of the necessary lupus medication can cause anxiety, personality and mood changes, forgetfulness, and other psychological problems. Some neuropsychiatric problems, such as those listed in a previous section, are caused by lupus, not with the stress of having it.

- Know what signs to look for and keep open communication with your doctor about them.
- Let your family and friends know about the possible side effects so that they may help as well.

Stress can also make you more prone to fatigue and illness. While it may be in your nature to do it all, you may need to delegate some of your tasks or let them go. A busy schedule can decrease your sleep, cause poor nutrition habits, and leave little time to catch your breath. This is a perfect recipe for a flare-up. Remember, the healthier you are, the better you will be to do the things you want to do.

- Make necessary health habits like sleep, nutrition, and stress-free moments a priority.
- Find way to delegate certain tasks. Ask for help from family or friends to help reduce stress.
- Find activities or treatments that help you decrease stress. Consider a massage, a good book, or some quiet time.

### **Medical Shuffle**

There is a lot of information to absorb about your disease, steps for management, and medical care. Become a partner with your doctor. Keep an open dialogue about your lupus management. Open and honest communication can help you both create the best treatment plan for you.

- Take the time to understand why certain medications, treatments, or procedures are being recommended.
- Talk to your doctor about the course of the disease and what signs or symptoms you should be aware of.
- Keep your doctor apprised of information you learn from tracking your behaviors and symptoms.
- Ask about treatments, studies, or problems you have come across. Information flowing both ways will help create a complete picture of your health and care options.

Regular visits to your doctor when you are healthy may help find problems before they start. If you only see your doctor for emergency situations, you will always be playing catch-up. Preventive care, such as immunizations, will help ward off infections like the flu which can

trigger flare-ups. Maintenance of your overall health will help you feel well and may prevent more serious complications from developing.

### **Personal Relationships**

Managing a chronic disease can be difficult for you, your friends, and family. Common lupus symptoms like fatigue and joint pain are not visible to others. Some may have a hard time understanding how lupus is affecting you. Help your friends and family understand the disease process so that they may be able to participate in your healthy lifestyle. Use brochures, lupus websites, or other written material to explain the disease process to them.

Your lifestyle may change now and during future periods. Keep communication open with family and friends as changing responsibilities and roles may affect them as well. Honest communication will help dispel fears, confusion, and frustration for you and your family.

Find support groups that fit your needs. The people that most understand what you are going through are going through the same thing. A lupus support group can provide emotional support and coping success stories.

The good news is that most people with lupus can maintain a high quality of life. Work to make changes in line with your goals. The exact path of the disease is not always predictable despite best efforts. Know that future plans may need to be adjusted. Make the choices that are right for you, leave flexibility in your plans, and communicate openly.

Source: <https://www.excelahealth.org/health-library/article?chunkid=462521&lang=English&db=hlt>

## EXPLAINING LUPUS PAIN AND FATIGUE

Interacting with family and friends who don't understand what it's like to live with lupus is one of the most challenging experiences when coping with the disease.

They might insist that fatigue is simply being tired and blame your time in bed as your own laziness, or your lack of not trying hard enough to get up. They might take it personally and become angry that you have had to repeatedly cancel plans due to fatigue or a flare. This might cause them to become angry or eventually cut ties with you.

When loved ones don't understand lupus, especially major, common symptoms like fatigue and pain, interacting with them can be difficult. Finding ways to help them understand pain and fatigue could help your relationship with them.

### **1. Be Specific About Pain Symptoms**

Pain can mean different things. When describing your pain, be specific about the type of pain you're experiencing. For example, is it a sharp pain? A stabbing pain? A dull ache? A burning sensation? Every time someone touches you, does it feel like they're pressing into a bruise even when there is no actual bruise?

In addition, explain where the pain is located. Is it all over your body (widespread pain)? A sharp stomach pain? Joint pain? Back pain? Knee pain?

Explain how it impacts you. Do you have trouble getting out of bed in the morning due to joint pain and muscle stiffness? Does it hurt to write with a pen? Is there a stabbing pain in your knees when you walk?

Here are a few examples of how to explain your pain to someone:

"It's hard for me to walk. I have a sharp, stabbing pain on both sides of my hips."

"The stiffness in my muscles and joints causes me pain when I move. When I try to get out of bed in the morning and stretch and unfold my limbs, it feels like I'm prying them apart. They feel swollen and achy. I feel like the Tin Man because they feel frozen in place, which is scary, but also requires that I get out of bed slowly."

"My whole body feels like a giant bruise. I mean no offense, but please don't touch me. Even gentle touch can be painful for me."

"The joints in my feet feel like they are on fire. It hurts to walk."

## **2. Describe Fatigue in Ways People Without Lupus Can Relate To**

Fatigue is challenging for people to understand who have never experienced it. The word fatigue is used in everyday conversation by people without chronic illness as a way to explain that they are very tired. This only adds to the confusion about fatigue.

A good way to help them understand fatigue is to describe it in a way that relates to something they have experienced or can imagine. Otherwise, the idea of fatigue tends to be too abstract and vague.

Fatigue, even for people with chronic illness, comes in different intensity levels.<sup>1</sup> Find examples that apply to your situation.

*Example #1:* Since everyone has had a bad cold or the flu at some point in their lives, using these experiences as examples usually works. Say something like, "You know how you feel when you have a fever? Your whole body is drained of energy and aches all over. No matter how much you want to get out of bed all you can do is lie there or sleep? When I say I'm fatigued and can't get out of bed, that's similar to how I feel. Except, I don't have a cold or the flu. Lupus causes my fatigue."

*Example #2:* Another common experience is feeling exhausted after overdoing exercising. You could say something like, "Have you ever pushed yourself too hard while working out and all you do afterward was go home and lie on your couch and watch television? Imagine that, except instead of a one- or two-hour workout, how might you feel after a 26-mile marathon? That's how it feels for me sometimes. There are days when I wake up and all my muscles ache like I ran 26 miles the day before. Except, all I did yesterday was go to work. I wanted to go to work today, but I could barely make it to the bathroom to brush my teeth."

*Example #3:* There might be examples from your life if you have experienced something that you can describe in a way that others without lupus can imagine and understand.

For example, "I wanted to go to the gym, but by the time I got dressed and drove there, all I could do was put two chairs together and lie there for two hours. That's fatigue."

*Example #4:* The Spoon Theory: Christine Miserandino's Spoon Theory has been highly successful in helping people explain fatigue not only in the lupus community but in chronic illness communities where fatigue is a major symptom. It's available in multiple languages, easy to read and understand, and you can download a copy and hand it out to friends and family to read.

### **3. Ask for Help**

There will be times, especially during a flare, that you will need help. Typically, the more your loved ones understand what you are going through, the more supportive they can be—the more supportive they will want to be.

For some, asking for help is often easier said than done, but don't be afraid to ask for help. Your loved ones want to help you. It gives them a way to stay involved in your life and a concrete way to offer you support.

Be clear about what you need from them. What you need might seem obvious to you, but not to them. For example, you might say, "I need you to remember that when I cancel plans, it has nothing to do with you. More than anything, I want to go out. If I cancel please try to understand that it's because I don't feel well, and please continue to be my friend and continue inviting me places."

And when your loved ones are helpful and supportive, acknowledge their help. This helps them recognize that their behavior was helpful to you, but also a thank you goes a long way.

### **4. Explain Mood Changes**

Both pain and steroids can cause behavior changes.

Pain can cause so much discomfort it can negatively impact a person's mood. Also, steroids can cause irritability and mood swings.<sup>2</sup> Let your loved ones know not to take your behavior personally, and be clear with them about what you need from them to help you get through these experiences.

It's also a good idea to speak with your rheumatologist if you are experiencing pain intense enough to impact your moods or if steroids are causing behavior changes.

### **5. Invite Loved Ones to Support Groups and Lupus-Related Events**

An excellent way for your loved ones to get a better understanding of lupus is to be involved in the lupus community. Hearing the experiences of others with lupus at support groups and attending lupus education events will help them learn more about the disease and how it impacts people's lives, including yours.

## **6. Know When to Let Go**

People aren't always responsive to your attempts to communicate with them about your life with lupus. They might continue to call you lazy, not believing your symptoms because you don't look sick. They might relentlessly offer misguided advice that you can pray away your disease or cure it with a special diet. They might disappear.

None of this type of behavior is your fault.

For example, their well-intentioned but misguided advice tends to come from a place of true concern for your well-being and their own wish for you to be okay because they love you.

Sometimes it's that they're afraid of what might happen to you, and this fear is more powerful than their ability to cope. Or maybe they've convinced themselves that being there for you is just too complicated.

They might continue to take it personally when you cancel plans.

Everyone responds differently to their loved one's illness, and the way they respond to your life with lupus has to do with how they cope with such realities.

Because of this, some people are unable to give you the support you need. Or some people might be limited in giving you support. Maybe they can't be the listener that you need when you are having a bad day, but they are excellent company when you need a good laugh.

Other people become unsupportive to the point of becoming toxic to you. It's important to know that you are allowed to distance yourself from and limit communication with people who you feel are emotionally unhealthy to be around.

And grief is a normal response to this relationship loss. Unfortunately, this is not a rare experience when it comes to living with a serious chronic illness, so sharing your story with your support group will sound familiar to many people. Sharing your story could also help you cope with the loss.

## **7. Use "I" Statements**

Use "I" statements instead of "You" statements. They are a gentler way to handle confrontations and help reduce the other person's level of defensiveness. For example, instead of saying "You're cruel to constantly accuse me of being inconsiderate when I canceled plans," you could try something like, "I felt hurt when you accused me of being inconsiderate for canceling plans. If I could have gone out, I would have, but I was feeling so bad, I had to stay in bed. Trust me, I would have much rather preferred to feel well and go out with you than to feel the way I did."

## **8. Good Communication Goes a Long Way**

Just like it is important to learn how to communicate well with your doctor, it's important to use these communication skills with your friends and family. While it might feel like work, it can help improve your relationships and also the level of support they give you. In turn, this can help improve your life with lupus.

Source: <https://www.verywellhealth.com/explaining-lupus-to-friends-and-family-4067137>



**RESEARCH & RESOURCES**

**LUPUS**  
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**APPLY NOW**

**APPLICATIONS DUE: APRIL 16, 2021 AT 5PM**

**GARY S. GILKESON CAREER DEVELOPMENT AWARD**  
*Four grant awards of up to \$70,000 each for up to 2 years*

**GINA M. FINZI STUDENT SUMMER FELLOWSHIP PROGRAM**  
*Six fellowship awards of \$4,000*

**LUPUS CANADA CATALYST GRANT**  
*One Catalyst Award for a total of \$35,000 CDN\**

## **Lupus Foundation of America Accepting Applications to Fund Critical Lupus Research**

### **Apply Now!**

The Lupus Foundation of America is pleased to announce that they are accepting grant applications for three critical awards aimed to develop the next generation of lupus scientific leaders. All three awards aim to cultivate and support early lupus researchers and encourage the brightest and most innovative scientists to pursue a career in lupus research. We need more trained researchers to help us solve the cruel mystery of lupus.

### **GARY S. GILKESON CAREER DEVELOPMENT AWARD**

Four grant awards of up to \$70,000 each for up to two years.

The Gary S. Gilkeson Career Development Award facilitates the professional development of current fellows (any year), clinicians up to two years post-fellowship and/or within four years of Postdoctoral research in nephrology, rheumatology, or dermatology, in the U.S. or Canada. Their work should focus on the investigation of basic, clinical, translational, behavioral, or epidemiological lupus research.

### **GINA M. FINZI MEMORIAL STUDENT SUMMER FELLOWSHIP PROGRAM**

The program will award six summer fellowships of \$4,000 each.



The award will foster an interest among students in undergrad and graduate programs who are interested in research relevant to lupus. Students are required to identify and work under the supervision of a qualified investigator in the U.S., Canada, or Mexico.

### **LUPUS CANADA CATALYST GRANT**

One Catalyst Award for a total of \$35,000 CDN\* to fund one project for a term of one year.

The Lupus Foundation of America has partnered with Lupus Canada for the second year to offer the Lupus Canada Catalyst Grant. The Catalyst grant is intended to help kick start a new project or research idea focused on discoid or systematic lupus erythematosus (SLE). This grant provides support to Canadian investigators to initiate new research ideas and projects and is intended to complement rather than compete with traditional sources of funding such as the Canadian Institutes for Health Research (CIHR).

**Applications are due April 16th, 2021 at 5PM EST**

*To learn more about each grant and how to apply, please visit [lupus.org/research/apply-for-funding](https://lupus.org/research/apply-for-funding)*





## Crispy Honey Garlic Salmon

PREPARATION: 20MIN

COOKING: 6MIN

SERVES: 6

### INGREDIENTS

- 2 tablespoon honey
- 1 tablespoon lemon juice
- 2 -3 large garlic cloves, grated
- ½ teaspoon salt
- ½ teaspoon ground black pepper
- Six 3 oz each salmon fillets, skin on/off
- 1-2 teaspoon avocado oil
- 2 green onions, finely chopped

### DIRECTIONS

In a small bowl, whisk together honey, lemon/lime juice, garlic, salt and pepper

Place salmon fillets in a large resealable Ziploc bag and pour marinade over. Squeeze as much air out as possible and seal the bag. Gently move fillets around inside the bag to make sure they are all evenly coated. Place flesh side down and let marinate 15 minutes

Preheat large non-stick skillet on low - medium heat and add oil, making sure it coats the bottom of the skillet evenly. Place salmon fillets flesh side down leaving enough space in between them. Cover with a lid and cook for 3 minutes

Remove the lid, cook another minute and flip over. Repeat: cover, cook for 3 minutes, remove the lid and cook for another minute. If your skillet is not large enough I recommend cooking in two batches. If you over crowd the skillet, cooking time increases by a few minutes for each step. Serve hot garnished with green onions alongside quinoa and steamed broccoli.

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

Source: <https://ifoodreal.com/honey-garlic-salmon/>

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