



## December E-Newsletter

### *Happy Holidays*

It is time to bundle up during this cold month of December. This month is dedicated to spending time with family and friends, though it can also be a time where stress can be overwhelming. Try and take sometime this month for yourself and to also enjoy all the special moments with your loved ones.

### DONATE TODAY

Still thinking what to give that special someone? A gift of "In Honour" is always a great way to honour that special someone in your life. In Honour gifts are donations made to celebrate and honour a special occasion or person, or mark a life milestone. A personalized acknowledgement card will be sent to the honouree or family by Lupus Canada if directed. You will receive a tax receipt for your donation. For more information on how to donate to Lupus Canada please visit <http://www.lupuscanada.org/ways-to-donate>.

### NEW APPOINTMENT



Lupus Canada is pleased to announce the promotion of our National Manager, Leanne Mielczarek, to the position of Executive Director. Through Ms. Mielczarek's commitment to the organization, lupus awareness in Canada has risen, and we look forward to the knowledge, energy and dedication she will bring to her new position. advocacy.



## MY LUPUS STORY by Jillian Cooper

I was diagnosed with Lupus when I was 17...a terrible time to deal with the symptoms like extreme fatigue and joint pain. I had to drop out of high school and I lost my job...I couldn't function and for a 17 year old that was devastating. After more than a year of different pain meds and being told I was a typical lazy teenager my family doctor called me into her office, "well Jillian...I have good news and bad news! The good news is we know what's wrong with you, the bad news is it's Lupus." End of discussion. I thought I was dying of cancer! I fell into a huge depression until my wonderful angel of a Mother pushed to get me into one of the top Lupus clinics with one of the top specialists. Sure enough I had Lupus and I needed to quickly learn how to deal with that. We weren't sure where this journey was going to take me, I may require a wheelchair or my other organs may be attacked. We could only go day by day and monitor this very closely! After trial and error we found the right medication. I had no choice but to live my life to the best of my ability...until one day I decided that wasn't enough....I was going to win and not let Lupus beat me. I started running, I ran further and I ran faster and in 2010 I ran the New York Marathon (and I ran it well). I was determined to beat Lupus. I am now a wife to an amazing husband and a Mother to the most perfect little boy (with another on the way). There have been many ups and downs in the years since being diagnosed but I refuse to let Lupus win.

## Lupus Fog and Memory Problems

<http://www.webmd.com/lupus/features/lupus-fog-memory-problems#1>

***The exact cause of lupus fog is hard to pin down, experts say. In some cases, lupus can damage cells in the brain, leading directly to cognitive problems. However, in most cases other factors play a role, including fatigue, stress, and depression. Lupus fog is sometimes worse in people who also have fibromyalgia.***

By R. Morgan Griffin

From the WebMD Archives

**Lupus** fog -- the forgetfulness and fuzzy-headed feeling that can come with **lupus** (systemic lupus erythematosus, or SLE) -- can be one of the most frustrating symptoms of the condition.

The term lupus fog means more than memory problems. It also refers to cognitive difficulties, such as trouble helping your child with homework, or writing a grocery list.

"It can really make your whole world fall apart," says Janet Foley Orosz, PhD, a public policy expert in Ohio who has struggled with lupus fog for almost 20 years. She's now collaborating on a web site and vocational program designed to help others with the condition.

There's no cure for lupus, so there's no cure for lupus fog either. But there are ways to work around your problems with concentration and memory. Here's what you need to know.

## What Is Lupus Fog?

Lupus fog is a general name for the cognitive impairments that often appear with lupus, including concentration and memory problems, confusion, and difficulty expressing yourself. These cognitive problems are often worse during flares.

The good news: Lupus fog doesn't usually get progressively worse, like [dementia](#) or [Alzheimer's disease](#), says Lisa Fitzgerald, MD, a [rheumatologist](#) at the Lupus Center of Excellence at the Beth Israel Deaconess Medical Center in Boston. Instead, memory issues will probably wax and wane, just like other [lupus symptoms](#).

The exact cause of lupus fog is hard to pin down, experts say. In some cases, lupus can damage cells in the [brain](#), leading directly to cognitive problems. However, in most cases other factors play a role, including [fatigue](#), stress, and [depression](#). Lupus fog is sometimes worse in people who also have [fibromyalgia](#). Although it's possible that side effects from drugs such as [NSAIDs](#) or steroids could worsen lupus fog, experts say that switching medicines rarely resolves the problem.

While researchers study possible [causes of lupus](#) fog, Orosz focuses on coping strategies that help people deal with it.

"When you're a person [dealing with lupus](#) fog, you don't worry that much about what's causing it," says Orosz. "What you care about is learning how to work around it."

Here are some tips that may help you deal with lupus fog.

## Tips to Improve Lupus Fog Symptoms

**Put it in writing.** "It's really important to lighten the load on your working memory," says Orosz. Instead of trying to keep stuff in your head -- and failing -- write it down. Write everything down -- every household chore, every birthday, and every doctor's appointment. Take notes during conversations. You need to get in the habit of writing down even the stuff you're positive you would never forget.

**Stay organized.** Keep everything in a daily planner so you don't end up with your notes on random scraps of paper. Consult it many times a day. Come up with a schedule and manageable to-do list -- or even just one specific goal -- for every day. If you have a smart phone, get a good note-taking app that you can access on your phone and on your computer.

**Prioritize.** "I divide tasks into two categories -- things I must do and things that would be nice to do," Orosz says. "Then I only do the must-dos." She says an alternative way to organize is to rank to-do items by how much stress they're causing and to get rid of the stressful stuff first.

**Say it out loud.** "Things seem to stick better in the short-term memory if you say them aloud," says Robert Katz, MD, a rheumatologist and associate professor of medicine at Rush Medical College in Chicago. When you meet new people, use their name a few times in the conversation. After a chat or meeting at work, repeat the main points -- it will help solidify your memory and let others fill in anything you missed.

**Time yourself.** Orosz says that people with lupus fog should figure out when they're most efficient and schedule important tasks for then. Maybe it's a particular time of day or after a [medication](#) dose. Keeping track of time can help in other ways. "Allot a specific amount of time for a task and keep yourself to it with a timer," she says.

**Stretch your memory.** Playing word games and doing crossword puzzles can help sharpen your memory. "Many of the techniques that help older people who are getting forgetful will also benefit people with lupus fog," Fitzgerald says. Keep your mind active and engaged.

**Keep good habits.** If you have lupus, you need to take care of yourself. Reducing stress, taking naps, and getting [enough sleep](#) at night could help relieve lupus fog symptoms. "Regular [exercise](#) is important," says Fitzgerald. "It does seem to make the [brain](#) sharper."

## Getting Expert Help for Lupus Fog

When it comes to lupus fog, don't go it alone. Experts can help teach you ways to work around the cognitive symptoms.

Orosz suggests getting a referral to a neuropsychologist. Other types of experts who may help you cope with lupus fog include vocational counselors, cognitive therapists, and some occupational therapists.

Make sure these specialists have experience helping people cope with concentration and memory problems. They don't need to be experts in lupus specifically. Other conditions – such as MS and [fibromyalgia](#) -- can cause similar types of concentration and

memory problems. But the specialists do need to know how to help people with [brain](#) fog.

Pay attention to the costs. Insurers will hopefully cover a referral to a neuropsychologist, Orosz says, but coverage for cognitive therapy or occupational therapy might be more limited.

## Living with Lupus Fog

- **Be honest with yourself.** If your lupus fog symptoms are mild, you might not need to alter your routine much. If your lupus fog is severe -- or long-lasting -- you might need to consider big changes to your life and career.

That's not easy. Just remember that trying to maintain a schedule that's become too demanding -- and living in a state of [panic](#) and [anxiety](#) -- will make you miserable. It will affect your family. It could very well worsen your lupus too.

"Having lupus fog will force you to change your expectations sometimes," says Orosz. "It can be really hard to let go." But making a big and necessary change will likely benefit you and your family in the long run.

- **Be open with your family.** Have an honest conversation with your loved ones about lupus fog. Make clear that lupus fog is not dangerous. It will probably come and go. They also need to understand that when things slip your mind -- like a child's soccer game or recital -- it's a symptom, and not because you don't care.

Enlist your loved ones' help in supporting your memory. Ask them to use notes, texts, or email to remind you of things, instead of just telling you. You and your spouse may need to change how you divvy up responsibilities too.

- **Consider talking to your employer.** Lupus fog can be especially hard to manage at work, where concentration and memory problems might make you look lazy or unreliable. Some people with lupus decide to talk to their managers about the problem.

Plan for the conversation. You need to know what you want to say and what you want to ask for. Some modest changes -- modifying your hours or allowing for a little extra time on certain projects -- may help. Before the talk, you may also want to talk to a counselor -- about your rights under the Disabilities Act.

- Having lupus fog can be terribly discouraging. It can undermine your confidence and even your sense of self, Orosz says. It's important to remember that it's not you. Lupus fog is just another lupus symptom -- like achy joints or facial [rash](#).
- Don't despair and don't settle for the symptoms. Talk to your doctor and see if you can get a referral to someone who specializes in [treating lupus](#) fog. The right treatments will help you feel better and more confident again.
- WebMD Feature Reviewed by [Brunilda Nazario, MD](#) on December 15, 2010

## The Holidays with Lupus

### **Coping with (and enjoying) the holidays with Lupus**

The holidays can be equally exciting and stressful for people with or without lupus. And of course, this depends on a huge variety of factors, like whether or

not you are spending them with your family or alone, and how you're feeling at that time. Between getting all your preparation done for your regular job, holiday shopping, cooking, traveling and prepping to host family and friends or visiting family and friends, the entire season can feel all too overwhelming.

During this time, it is especially important to listen to your body and what it is telling you and not to stress yourself out too much.

### **Visiting Family and Friends**

When I visit family and friends during the holidays, I make certain they know that I am going to need time to rest. Most of my family and friends are very aware of my lupus, so typically it isn't an issue and most people will be flexible (if they're good friends, that is).

Of course, not everyone is going to be and some people may take your illness personally or even accuse you of being ill at certain times either to spite them personally, or because you're trying to get out of an event. I have been accused of this several times over the holidays, particularly when getting together with extended family I haven't seen in years and who doesn't see how my lupus operates on a daily basis.

Because lupus is so fickle, it can be difficult for others to understand, which will stress you out and then in turn make you feel worse. Personally, I choose to stop seeing friends that are not understanding about lupus after giving them a good benefit of the doubt, but sometimes you can't do that with family. Instead, even though it is irksome, you just have to smile through your teeth and go rest when you need to. Really, your body is more important than the opinion of your 76-year-old great uncle you only see twice a year. Use Elsa from Frozen's motto and "Let it go!"

## **Gift Shopping**

Shopping for the holidays season can be stressful for lupus patients, as it often involves lots of walking, standing around and potentially spending money that you don't have. If you're short on cash from being unable to work, try making something for your friends or family members. It may not be as "wow" as an iPad, but it will be treasured for longer than one year (when they need the new iPad that will inevitably be coming out).

Making something doesn't have to mean a fancy Pinterest-worthy DIY (those make my self-esteem rot when I attempt them). You can do things like write short stories, poems or give baked goodies to the people of your choice. You can even put together inexpensive pamper packages for your friends by purchasing a mug, some marshmallows, hot chocolate packs and candy canes and putting them together. It is a quick and easy idea that doesn't take much time or effort and they'll be grateful you thought of them!

To minimize my own stress, I try to do all of my shopping online weeks in advance. This way everything gets delivered to my door. It is easy and simple and helps you avoid long lines and crowded malls.

## **It's OK to say NO**

Above all, be kind to yourself. Don't make commitments you're iffy about keeping. If your son's teacher wants you to make four dozen cupcakes for the school Christmas party, don't be afraid to say no. If your pastor asks you to come help decorate for Christmas and your joints are swelling up that day, feel free to decline and stay home and rest.

Your health is more important than anything else this holiday season, and you'll want to ensure you can attend the commitments and parties and festivities that matter most to you. If you know you'll be too exhausted to wake up in time to see your kids open their gifts if you go to midnight mass, then skip it. If you know your mother-in-law drives you up the wall, plan to destress after Christmas dinner with a warm bath and some hot tea. Don't drive yourself crazy.

## **Being Alone**

While family and big holiday gatherings may be a source of concern for some with lupus (I always feel nervous to go places with people in case I start to feel sick and the other person wants to stay longer), for other people, the crippling loneliness of the holidays can be just as bad. Some of us don't have family to visit or can't travel home because of work commitments or financial constraints. And many people without family to visit can feel totally brushed aside by friends if they (understandably) cannot take too much time to be with you and need to attend to their own family commitments.

If this is the case for you, plan some activities for yourself so you don't let the depression set in. Even with lupus, you may want to get out and do activities in the community that help you meet people, or at least get you out of your own head. Check your local events calendar at your church or synagogue or other place of worship, as most will have meals and other events around the holiday season. It may feel awkward to go on your own, but you will definitely feel even a little bit less depressed after doing so.

And if you'll be alone on Christmas,

plan to go to a community holiday gathering or a church service just so you'll be around people. Even if you're not religious, the carol singing and festive food will help you feel less alone. And if you're able to, call a friend and see if he or she can drop by for a couple of hours on Christmas day. Make sure you buy some Christmas cake or make some hot chocolate for you and your friends stopping over if you're able to.

For me, finding time to relax is one of the most important aspects of the holiday season. In between the festivities and gift giving (or being totally alone, which I have, unfortunately done before), try to also schedule in some you time. I find that with lupus, I often neglect pampering and other things that most other people are able to do because I figure my excessive sleeping and relaxing is pampering enough. Instead of being in that mind-set, make time to give yourself a pedicure or get one done if you can afford it. Buy some bath bombs and have a soothing bath for an hour while sipping egg nog or hot chocolate. Do your nails while watching your favorite movie or a marathon of your favorite TV show. And most important of all, turn your phone off during that time so it is all about you!

I wish you a happy and healthy holiday season, whether it is spent alone or with friends and family.

source:

<http://lupus.newlifeoutlook.com/holidays-lupus/2/>



## Recipe corner

### *Roasted Brussels Sprouts and Grapes with Walnuts*

#### **Ingredients:**

- ❖ 24 ounces Brussels sprouts (about 8 cups), halved or quartered, if large
- ❖ 24 ounces grapes
- ❖ 2 tablespoons extra virgin olive oil
- ❖ 4 tablespoons fresh thyme
- ❖ course salt and freshly ground pepper
- ❖ 2 table spoons balsamic vinegar
- ❖ ½ cup walnuts, tasted and coarsely chopped

#### **Directions:**

- ❖ heat oven to 450 degrees. On 2-rimmed baking sheets, toss Brussels sprouts and grapes with oil and thyme. Season with salt and pepper. Roast, until caramelized and tender, about 20 mins
- ❖ Drizzle each tray with 1 teaspoon vinegar and scrape up any caramelized bits with a wooden spoon. Toss in walnuts.

Source:

[www.marthastewart.com/1050513/roasted-brussels-sprouts-and-grapes-walnuts](http://www.marthastewart.com/1050513/roasted-brussels-sprouts-and-grapes-walnuts)

## Cauliflower Mashed Potatoes



Find the recipe here

<http://steamykitchen.com/20966-cauliflower-mashed-potatoes-recipe.html>

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