

# Everyday Living with Lupus: Be Proactive



Title: *The Simple Task of Opening a Jar*

Caption: *How we cope with lupus.*

Photographer: Steve Edelstein

[lupuslens.wordpress.com](http://lupuslens.wordpress.com)

Jessica Rowshandel, LMSW

Director of Social Services

S.L.E. Lupus Foundation

# Proactive

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Being proactive means “creating or controlling a situation by causing something to happen rather than responding to it after it has happened: *be proactive in identifying and preventing potential problems*”<sup>1</sup>

<sup>1</sup>[Oxford Dictionaries: Proactive, definition](#)

# Potential Problems

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- Feeling or being sicker
- The ways that lupus impact different areas of your life

# Practice, not Perfection

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No one is perfect. Positive changes do not happen overnight and do not last without practice. Being proactive is a lifestyle, a practice.

# Control

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Control is not cut and dry. It's not that we either have control over things or we don't. There are grey areas. We might have some control over certain things, more for others, and almost all control over others.

# Control

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What you don't have control over?

# Control

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You have lupus.

# Control

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What do you have control over?



# Control and Coping

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Coping with lupus requires that you begin or continue to make choices that are **proactive** about what you have control over.

# Coping

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Coping is a learning and growing  
process.

# Coping

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You can learn coping skills.

# Coping

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The way you cope can help  
improve your **quality of life.**

# Coping

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The first step:  
Look at the big picture

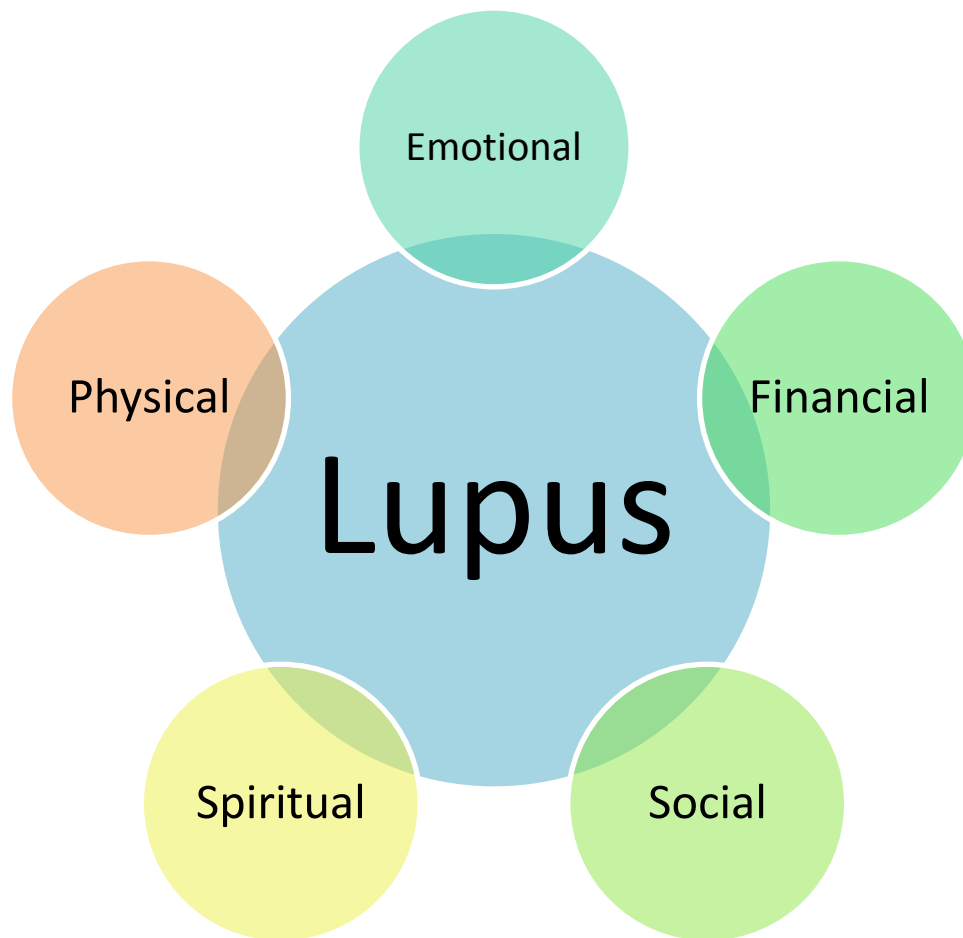
# Coping

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What are all of the areas in your life that lupus impacts?

# Coping

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# Coping

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Where do you have or can you take  
some control?



# Coping

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# Wellness

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Wellness is an “...active process of becoming aware of and making choices toward a healthy and fulfilling life.”<sup>2</sup>

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<sup>2</sup>[UC Davis, Health Topics – What is Wellness?](#)

# Wellness

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- a. An active process
- b. Become aware of your needs
- c. Make choices to help you feel better, to improve your overall health
- d. Physical, mental, social well-being

# Wellness

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- a. An approach to coping
- b. Daily practice
- c. Improves quality of life

# Coping Toolkit

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What tools are available for you to use to cope with lupus?

# Coping Toolkit

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- Being proactive means picking up these tools and using them
- The ideal toolkit versus what is realistic to implement
- Remember: Practice, not perfection
- Your choices, your preferences
- At your own pace
- Don't do everything at once

# Coping Toolkit

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- Some of these you already do
- Some require small adjustments
- Some require a larger effort
- For those that require more effort, choose one at a time
- Remember: Don't do everything at once

# The Big Three

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- Keep medical appointments
- Take medication as prescribed
- Find support



# Keeping Medical Appointments and Taking Medication as Prescribed

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- Helps manage flares and stabilize lupus and other conditions
- Helps detect and prevent organ involvement and damage
- Helps detect or prevent other conditions or complications
- Helps manage medication and side effects
- Without medical care and medication, much greater risk for severe complications

# Find Support

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lupus = emotional  
rollercoaster



# Find Support

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- You need to feel and express your emotions
- Without support, at risk for isolation and depression, especially with decreased socialization

# Find Support

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- It is hard for people without chronic illness to understand lupus
- Frustrating to be misunderstood by friends, family, and others
- If they understood, chances are they'd be more supportive
- It's ok to be selective about who to share things with, who to spend time with
- Need to find people who understand what it's like to live with lupus or who are willing to learn

# Find Support

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- There is healing in connecting with people who “get it”
- A relief to know you are not “crazy” or “lazy”
- A safe space to express emotions, even tears

# Find Support

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- Sharing of information, doctor recommendations, symptoms, daily experiences
- Learning how to cope from those who have more experience
- New friendships formed, camaraderie, positive emotional bonds
- Inspiration, encouragement

# Where to Find Support

Nationwide Partners | Lup

www.lupusresearchinstitute.org/partners



### Read Up if You Missed Affordable Care Act Webinar

Watch this slide presentation to understand more about how the Affordable Care Act will affect people with lupus, and how you can make a difference.



### Text to Give

Text LUPUS to 50555 to donate \$10 to research. Or text INFO to 50555 and opt-in to receive breaking news about lupus on your mobile phone.

Message and data rates may apply. Text STOP to 50555 to STOP. Text HELP to 50555 for HELP. Full Terms:



### In Your Community

Learn about local news and events from the LRI National Coalition.



### Clinical Trials to Consider

Visit [LupusTrials.org](http://LupusTrials.org) learn about lupus clinical trials that might be right for you or a family member.

### Connect with LRI

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Telephone Feedback

## Nationwide Partners

The Lupus Research Institute (LRI) National Coalition, the nation's leading lupus patient service organization representing the major urban centers across America, advocates on a national level on behalf of our patient and provider communities.

Our [National Coalition](#) of independent state and local lupus organizations, many in urban centers such as New York, Chicago, Los Angeles, and San Francisco

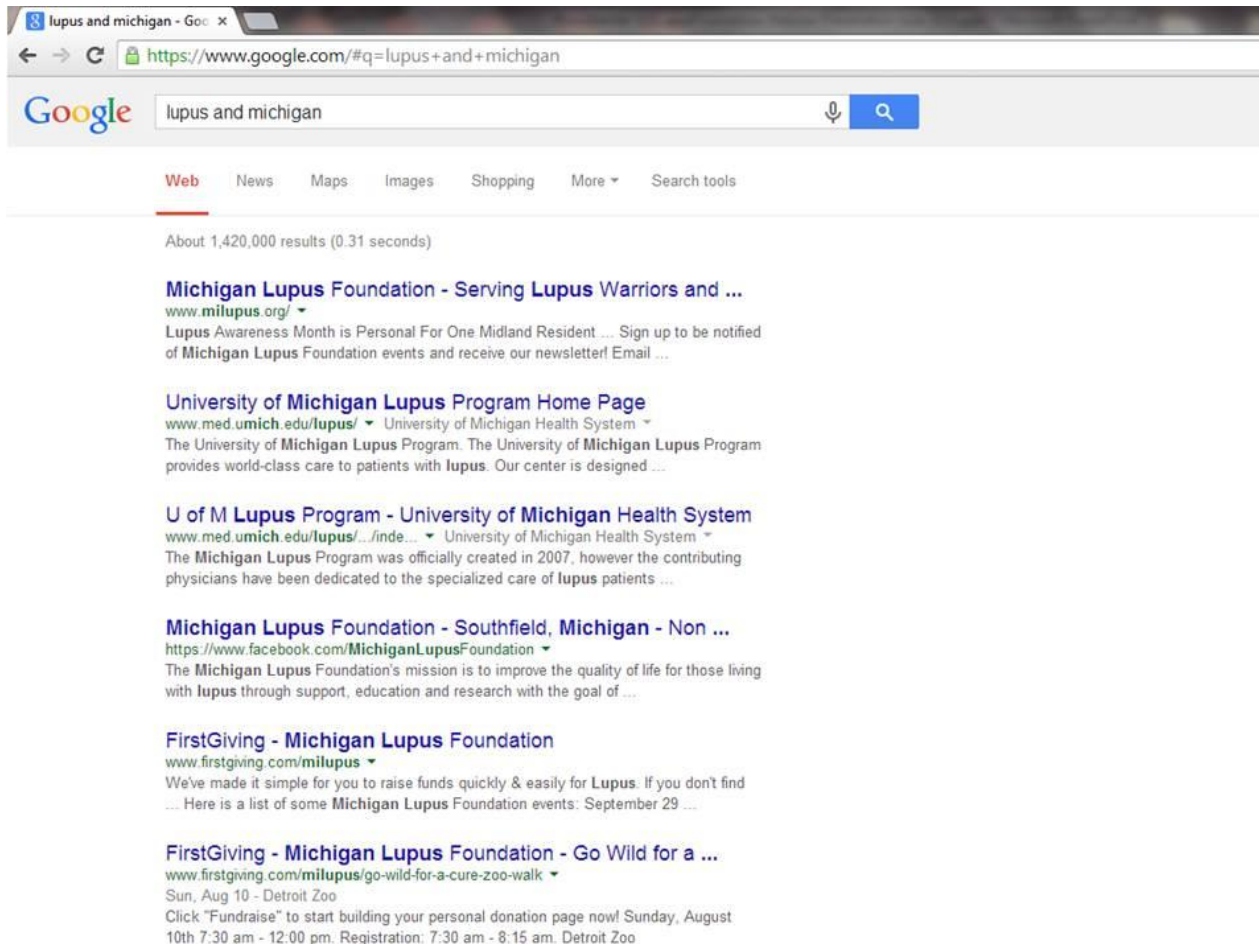
- speak as a united "patients' voice" for lupus research on Capitol Hill
- raise awareness and understanding of lupus
- care for people with lupus
- link people with lupus to clinical trials.

### LRI National Coalition

*Lupus Organizations Covering the Coasts and Major Urban Centers*



# Where to Find Support



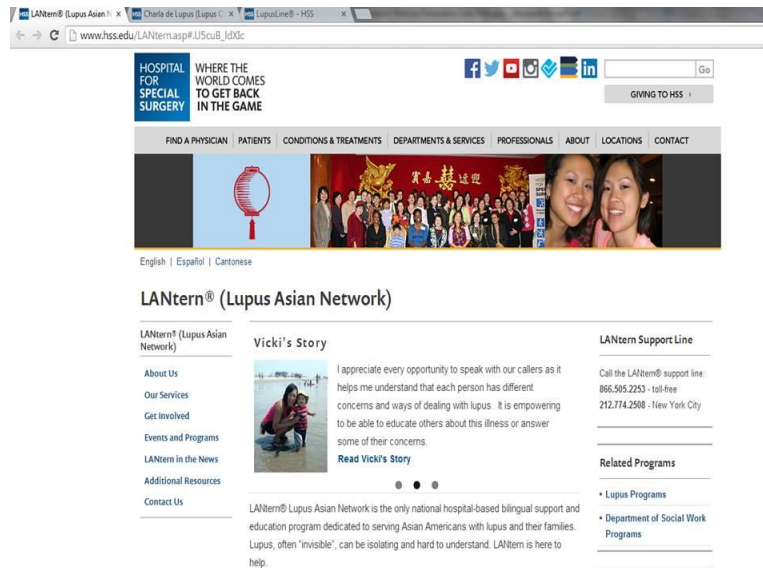


# Where to Find Support

Lupus Line: (866).375.1427

Charla de Lupus: (866).812.4494

LANtern (Lupus Asian Network): (866).505.2253



# Where to Find Support

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- One-on-one: a friend with lupus or a similar chronic illness
- In-person support group
- Lupus Line – National telephone peer support through the Hospital for Special Surgery, multi-lingual
- Online support groups/ Facebook groups
- Invite those in your life who are willing to learn more to attend groups, educational events, walks, online groups, etc.
- Individual psychotherapy. Ask the therapist if s/he has experience with lupus or chronic illness

# Special Support: Grief

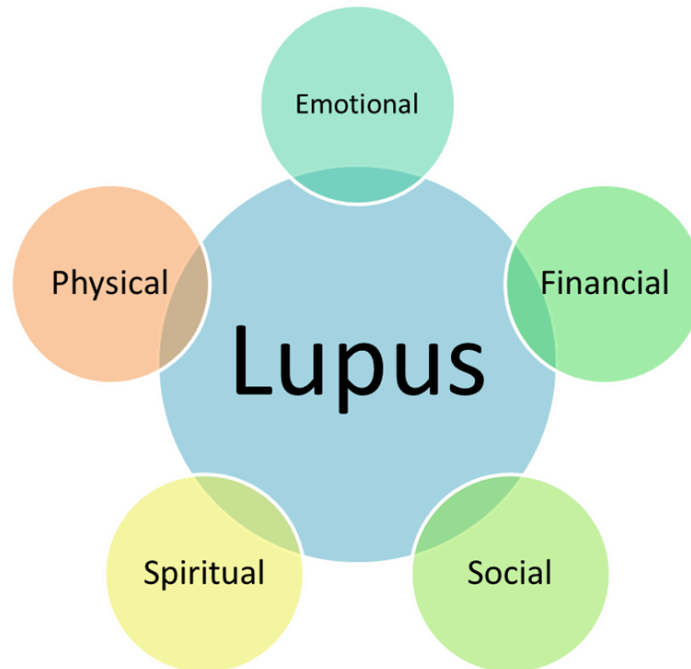
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Particularly important for newly diagnosed or those still struggling with coming to terms that they have lupus

# Special Support: Grief

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lupus = major losses



# Special Support: Grief

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Seeking support through the grieving process is important. Find a therapist who understands chronic illness, or a grief counselor.

# Special Support: Grief

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If you are seeking email support to help you with the grief you experiencing due to the losses you have incurred, contact **Barbara Rubel, MA, BCETS, a bereavement specialist**. Barbara can offer **free** grief support through email. Her email is [griefwork@aol.com](mailto:griefwork@aol.com). To learn more about Barbara, please visit her website [griefworkcenter.com](http://griefworkcenter.com).

# Special Support: Depression

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- Depression is a chronic condition. Symptoms include feeling hopeless, loss of interest in activities that you usually enjoy, feeling worthless, loss of interest in socializing, intense sadness, thinking about death a lot.
- If you feel depressed, tell your rheumatologist. It could be from lupus or a side effect of medication.

# Special Support: Depression

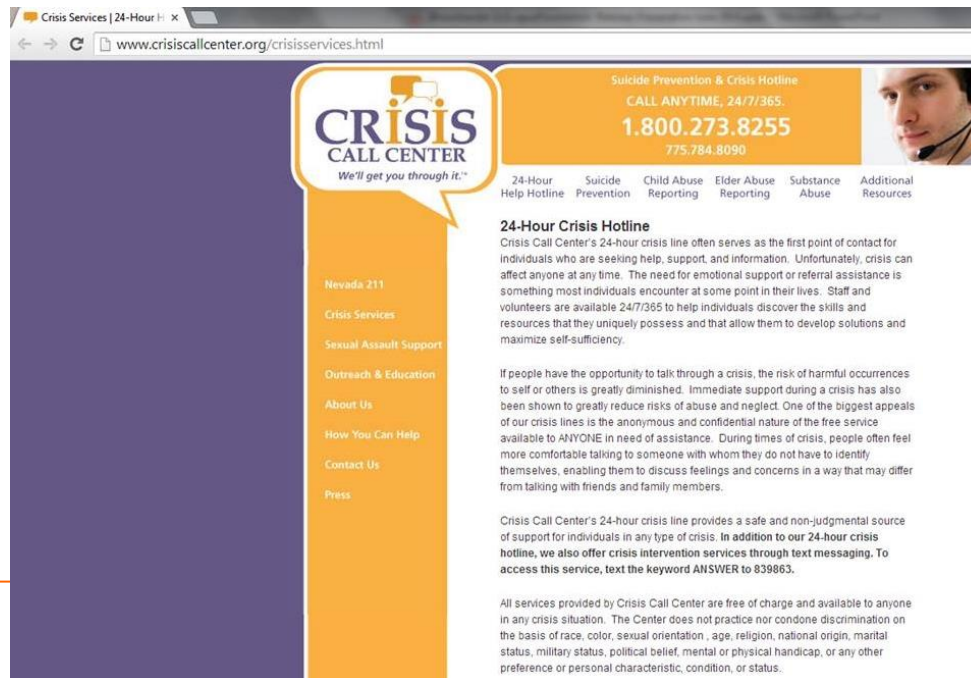
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- Support is important.
- Find a psychotherapist you like and, if possible, who understands chronic illness.
- When you call for an appointment, you can ask, “Do you have any experience with lupus or chronic illness?” Your rheumatologist, local lupus organization, or support group members might have some good recommendations.



# Special Support: Depression

If you feel like you are in an emotional crisis and need to speak with someone today, please call or text a crisis hotline: **call 1.800.273.8255 or text the keyword ANSWER to 839863**



The screenshot shows the Crisis Call Center website. The header includes the Crisis Call Center logo with the tagline "We'll get you through it." and a navigation menu with links for 24-Hour Help Hotline, Suicide Prevention, Child Abuse Reporting, Elder Abuse Reporting, Substance Abuse, and Additional Resources. The main content area features a section titled "24-Hour Crisis Hotline" which states that the crisis line is available 24/7/365 and provides information about the services offered. A sidebar on the left contains links for Nevada 211, Crisis Services, Sexual Assault Support, Outreach & Education, About Us, How You Can Help, Contact Us, and Press. The footer includes the S.L.E. LUPUS FOUNDATION logo.

Crisis Services | 24-Hour | x  
www.crisiscallcenter.org/crisisservices.html

**CRISIS CALL CENTER**  
We'll get you through it.™

Nevada 211  
Crisis Services  
Sexual Assault Support  
Outreach & Education  
About Us  
How You Can Help  
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Press

Suicide Prevention & Crisis Hotline  
CALL ANYTIME, 24/7/365.  
**1.800.273.8255**  
775.784.8090

24-Hour Help Hotline | Suicide Prevention | Child Abuse Reporting | Elder Abuse Reporting | Substance Abuse | Additional Resources

**24-Hour Crisis Hotline**  
Crisis Call Center's 24-hour crisis line often serves as the first point of contact for individuals who are seeking help, support, and information. Unfortunately, crisis can affect anyone at any time. The need for emotional support or referral assistance is something most individuals encounter at some point in their lives. Staff and volunteers are available 24/7/365 to help individuals discover the skills and resources that they uniquely possess and that allow them to develop solutions and maximize self-sufficiency.

If people have the opportunity to talk through a crisis, the risk of harmful occurrences to self or others is greatly diminished. Immediate support during a crisis has also been shown to greatly reduce risks of abuse and neglect. One of the biggest appeals of our crisis lines is the anonymous and confidential nature of the free service available to ANYONE in need of assistance. During times of crisis, people often feel more comfortable talking to someone with whom they do not have to identify themselves, enabling them to discuss feelings and concerns in a way that may differ from talking with friends and family members.

Crisis Call Center's 24-hour crisis line provides a safe and non-judgmental source of support for individuals in any type of crisis. In addition to our 24-hour crisis hotline, we also offer crisis intervention services through text messaging. To access this service, text the keyword ANSWER to 839863.

All services provided by Crisis Call Center are free of charge and available to anyone in any crisis situation. The Center does not practice nor condone discrimination on the basis of race, color, sexual orientation, age, religion, national origin, marital status, military status, political belief, mental or physical handicap, or any other preference or personal characteristic, condition, or status.

# Special Support: Depression

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If you feel like you need immediate help because you want to hurt yourself call 9-1-1 or tell a loved one to call for you.

# Special Support: Depression

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Without treatment, both depression and lupus can be dangerous illnesses. For both, with treatment, you start to feel better.

# Special Support: Depression

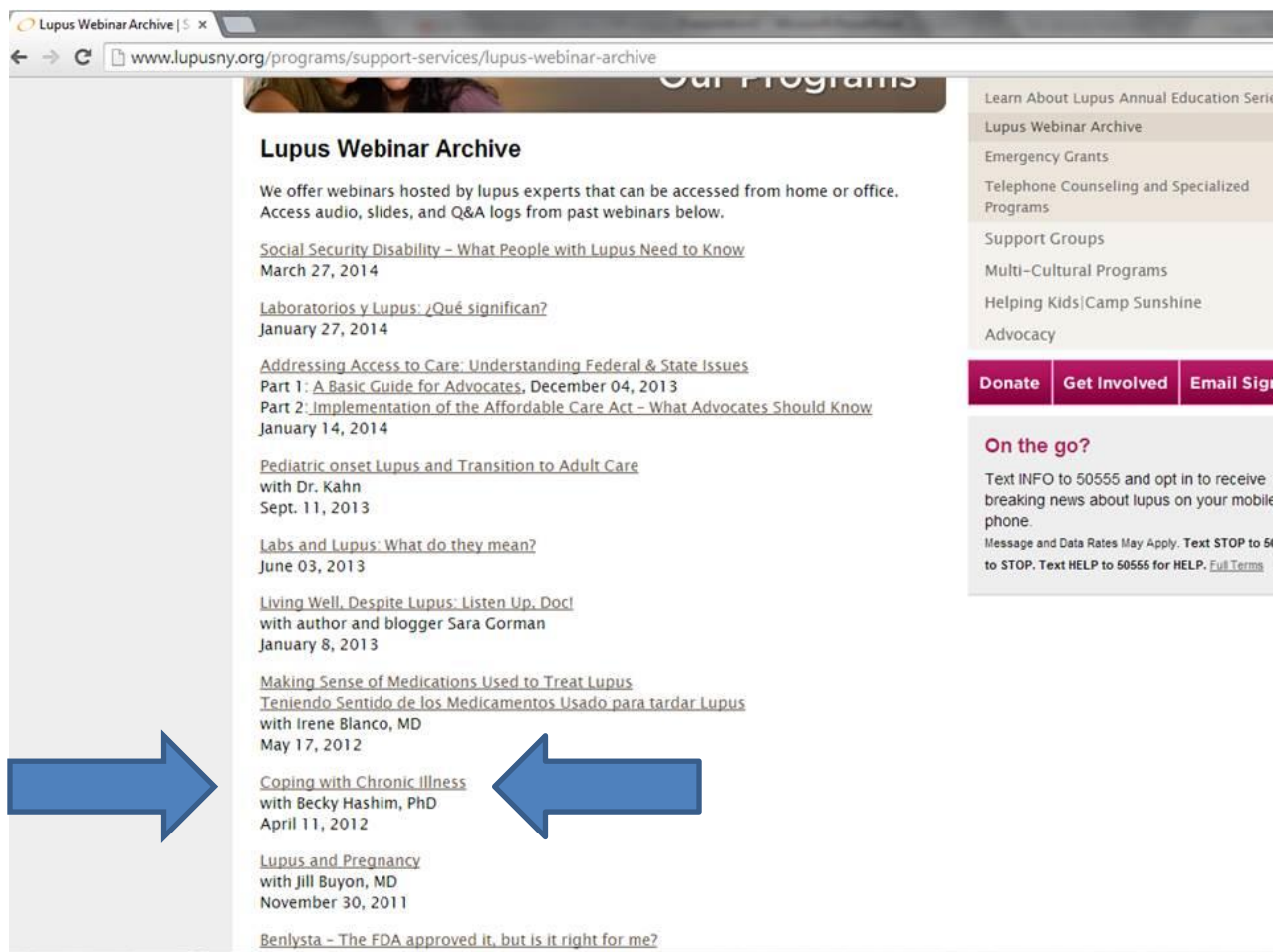
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Symptoms of depression can overlap with feelings of grief. Grief is a process and a normal and expected response to loss. Healing is possible for both.

# Special Support: Depression

CONDITION:	DEFINITION:	TIME OF ONSET/SYMPTOM DURATION:	SYMPTOMS:
<b>Stress Reaction</b> (Emotional Response)	<ul style="list-style-type: none"> <li>NOT a psychiatric disorder</li> <li>A "normal" reaction to a disaster, trauma or highly stressful life event</li> </ul>	<ul style="list-style-type: none"> <li>Symptoms occur immediately after and may continue for a period of time after the event</li> </ul>	<ul style="list-style-type: none"> <li>Disbelief and shock</li> <li>Irritability and anger</li> <li>Sadness</li> <li>Feeling powerless</li> <li>Feeling indecisive</li> <li>Crying</li> <li>Headaches or stomach problems</li> <li>Difficulty sleeping</li> </ul>
<b>Grief</b> (Emotional Response)	<ul style="list-style-type: none"> <li>NOT a psychiatric disorder</li> <li>A common, intense and painful reaction to loss, death of a loved one, family member or friend</li> </ul>	<ul style="list-style-type: none"> <li>Symptoms generally occur immediately, 1 month after, and up to 1 year from the time of loss</li> </ul>	<ul style="list-style-type: none"> <li>Numbness</li> <li>Loneliness</li> <li>Sadness, Guilt</li> <li>Shock</li> <li>Anxiety</li> <li>Anger</li> <li>Agitation</li> <li>Crying</li> <li>Insomnia</li> <li>Restlessness</li> <li>Withdrawal</li> </ul>
<b>Depression</b> (Psychiatric Disorder)	<ul style="list-style-type: none"> <li>A psychiatric disorder</li> <li>At least 2 weeks of depressed mood and/or loss of interest in typically enjoyable activities</li> </ul>	<ul style="list-style-type: none"> <li>Symptoms occur consecutively for at least 2 weeks more days than not</li> </ul> <p><i>Diagnosis may be delayed for 2 mos. after traumatic event in order to distinguish from grief.</i></p>	<ul style="list-style-type: none"> <li>Depressed mood</li> <li>Loss of pleasure or interest in enjoyable activities</li> <li>Feelings of guilt, worthlessness or hopelessness</li> <li>Loss of energy or fatigue</li> <li>Difficulty concentrating or making decisions</li> <li>Restlessness or irritability</li> <li>Changes in sleep patterns</li> <li>Changes in appetite/weight</li> <li>Thoughts of death or suicide</li> </ul>
Adapted from <a href="http://www.unhcc.unh.edu/resources/emotionsvsdisorders.html">www.unhcc.unh.edu/resources/emotionsvsdisorders.html</a>			

# Special Support: Depression



**Lupus Webinar Archive**

We offer webinars hosted by lupus experts that can be accessed from home or office. Access audio, slides, and Q&A logs from past webinars below.

[Social Security Disability – What People with Lupus Need to Know](#)  
March 27, 2014

[Laboratorios y Lupus: ¿Qué significan?](#)  
January 27, 2014

[Addressing Access to Care: Understanding Federal & State Issues](#)  
Part 1: A Basic Guide for Advocates, December 04, 2013  
Part 2: Implementation of the Affordable Care Act – What Advocates Should Know  
January 14, 2014

[Pediatric onset Lupus and Transition to Adult Care](#)  
with Dr. Kahn  
Sept. 11, 2013

[Labs and Lupus: What do they mean?](#)  
June 03, 2013

[Living Well, Despite Lupus: Listen Up, Doc!](#)  
with author and blogger Sara Gorman  
January 8, 2013

[Making Sense of Medications Used to Treat Lupus](#)  
[Teniendo Sentido de los Medicamentos Usado para tratar Lupus](#)  
with Irene Blanco, MD  
May 17, 2012

[Coping with Chronic Illness](#)  
with Becky Hashim, PhD  
April 11, 2012

[Lupus and Pregnancy](#)  
with Jill Buyon, MD  
November 30, 2011

[Benlysta – The FDA approved it, but is it right for me?](#)

Learn About Lupus Annual Education Series  
Lupus Webinar Archive  
Emergency Grants  
Telephone Counseling and Specialized Programs  
Support Groups  
Multi-Cultural Programs  
Helping Kids|Camp Sunshine  
Advocacy

[Donate](#) [Get Involved](#) [Email Sign Up](#)

**On the go?**  
Text INFO to 50555 and opt in to receive breaking news about lupus on your mobile phone.  
Message and Data Rates May Apply. Text STOP to 50555 to STOP. Text HELP to 50555 for HELP. [Full Terms](#)

# Special Support: Depression

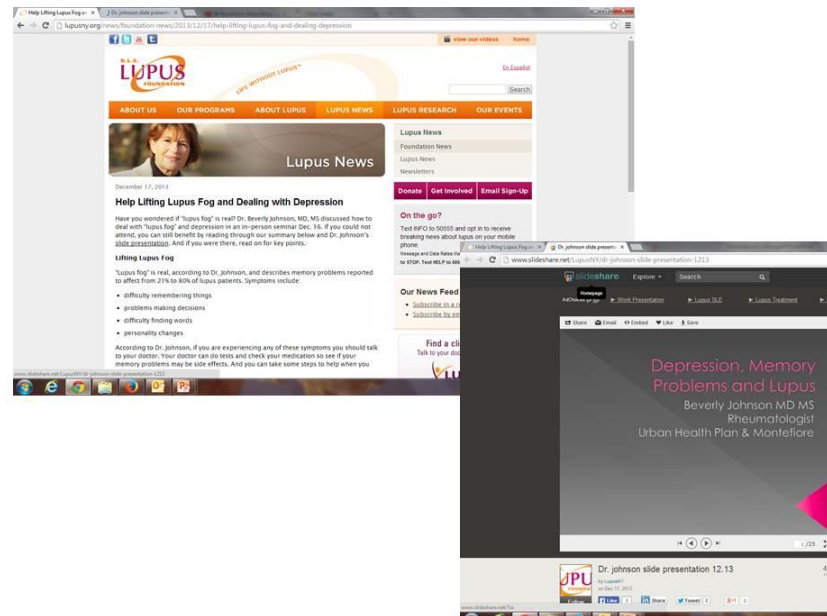
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In the webinar, Coping with Chronic Illness<sup>3</sup>, Psychologist, Becky Hashim, Ph.D., listeners learn about identifying stress, anxiety, and how to cope with lupus.

<sup>3</sup>[Coping with Chronic Illness, Becky Hashim, Ph.D.](#)

# Special Support: Depression

Rheumatologist, Beverly Johnson, MD, gave a talk for the S.L.E. Lupus Foundation on depression, memory problems, and lupus<sup>4</sup>.



<sup>4</sup>Help Lifting Lupus Fog and Dealing with Depression, Beverly Johnson, MD, MS



# More Important Tools

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A lot of options!

# More Important Tools

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- Nutrition
- Exercise and physical modalities
- Stress Management
- Sleep
- Scientific Literacy
- Communication

# Nutrition

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Speak with your doctor before making major changes to your diet.

# Nutrition

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- Don't drink alcohol in excess - check medication interactions, increased ulcer risk with NSAIDs , can never be taken if on Methotrexate, increased triglycerides, worsens bone density, empty calories<sup>5</sup>
- Don't smoke - smoking raises the risk for blood clots, heart disease and stroke, osteoporosis, stomach ulcers, Raynaud's symptoms<sup>6</sup>
- Eat real food - whole foods diet: less processed food, more fruits, vegetables, grains, nuts, beans, seeds, fish, lean meats, organic when possible<sup>7</sup>

[5, 6 Tools for Managing Your Lupus](#)

[7"Living Life Healthy with Lupus: Looking and Feeling Good" 2014](#)

# Exercise and Physical Modalities

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Before starting any new physical activity or modality, talk with your rheumatologist.<sup>8</sup>

<sup>8</sup>Exercise and Lupus

# Exercise and Physical Modalities

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Also know your own limits. Don't push yourself beyond them, especially if you have issues of mobility, flexibility, or pain.

# Exercise and Physical Modalities

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- Gradual, low-impact
- Restorative yoga
- Tai-Chi
- Water aerobics and Tai Chi
- Walking (Wear sun screen, SPF >30, UV A &B)
- Physical therapy
- Massage<sup>9</sup>
- Acupuncture<sup>10</sup>

<sup>9</sup>[Lupus Massage Therapy Resource Guide](#)

<sup>10</sup>[Acupuncture for systemic lupus erythematosus: a pilot RCT feasibility and safety study](#)

# Stress Management

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- Flare plan
- Meditation<sup>11, 12</sup>
- Gratitude<sup>13</sup>
- Self-compassion<sup>14</sup>
- Journaling or blogging

<sup>11</sup>[Meditation: A simple, fast way to reduce stress](#)

<sup>12</sup>[Sleep, Mindfulness Meditation, Relaxation and Stress Reduction Resources](#)

<sup>13</sup>[Giving Thanks Gives a Health Boost](#)

<sup>14</sup>[Wash Your Hands of Self-Criticism!](#)



# Stress Management

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- Spirituality
- Nature
- Laughter
- Hobbies – may not be the same as before
- Giving to others, volunteering

# Stress Management

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- Creative arts
- Energy management – know your limits, pace yourself, take naps
- Spend time with people whose company you enjoy
- Support Groups
- Psychotherapy (Social Worker: LCSW, Psychologist: PhD, PsyD, Marriage and Family Therapist: LMFT)

# Stress Management

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Pamper yourself!

# Stress Management

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When it comes to lupus and other chronic illnesses, things that are considered pampering are no longer that. They are like prescriptions. Do things that bring you joy and help you relax. It is required.

# Sleep

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- Get the sleep you need
- Talk to your doctor if you have trouble sleeping
- Relationship between fatigue, pain, and sleep<sup>15</sup>
- Sleep diary<sup>16</sup>, sleep diary app<sup>17</sup>

<sup>15</sup>[Pain Management in Lupus](#)

[Stuart Green, MD, Chief of Rheumatology at The Brooklyn Hospital Center](#)

<sup>16</sup>[Example sleep diary](#)

<sup>17</sup>[Example sleep diary app](#)

# Scientific Literacy

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Knowledge is power.

# Scientific Literacy

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- Learn as much as possible about lupus
- Make sure the sources are reliable (e.g., government agencies, hospitals, universities, reputable non-profit organizations)
- The internet is filled with misinformation
- Misinformation can confuse or even harm you
- Accurate information can empower you
- Patient education programs and webinars about lupus, research updates via Lupus Research Institute

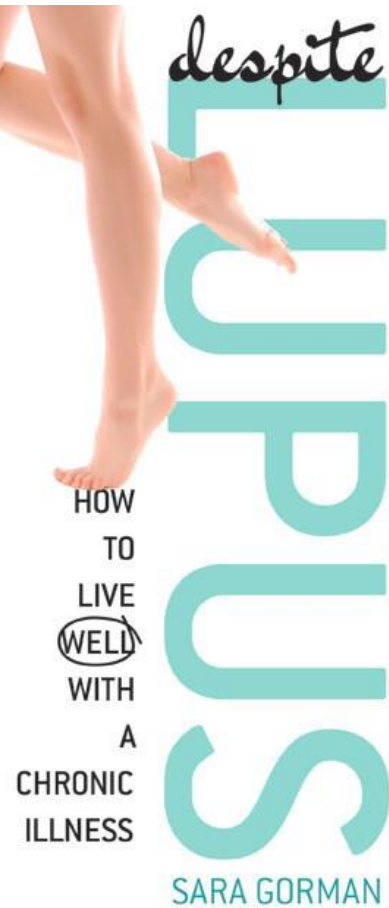
# Communication

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It is important to have good communication with your doctor.



# Communication



# Communication

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- Sara Gorman<sup>15</sup>
  - Be honest, open, assertive
  - Be prepared
    - Symptom journal
    - Written questions
  - Work as a team

<sup>18</sup>[Sara Gorman Webinar: Living Well, Despite Lupus: Listen Up, Doc!](#)

# Communicating with Friends, Family, and Others

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- Be kind
- Be clear
- Tell them your needs
- Bring them to a group, if possible
- Accept their limitations
- Share about mood changes with Prednisone use

# Revisiting Wellness and the Coping Toolkit

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- Physical well-being:
  - Medical appointments
  - Medication
  - Nutrition
  - Exercise and physical modalities
  - Stress management
- Mental well-being
  - Support through friends, family, groups, psychotherapy
  - Stress management techniques
- Social well-being
  - Support through friends family, groups, psychotherapy
  - Communication skills
  - Other social activities – Don't isolate!

# Quality of Life

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It is my professional experience that people who are proactive about coping with lupus have a better quality of life.

# Resources

Nationwide Partners | Lup

← → ↻ www.lupusresearchinstitute.org/partners



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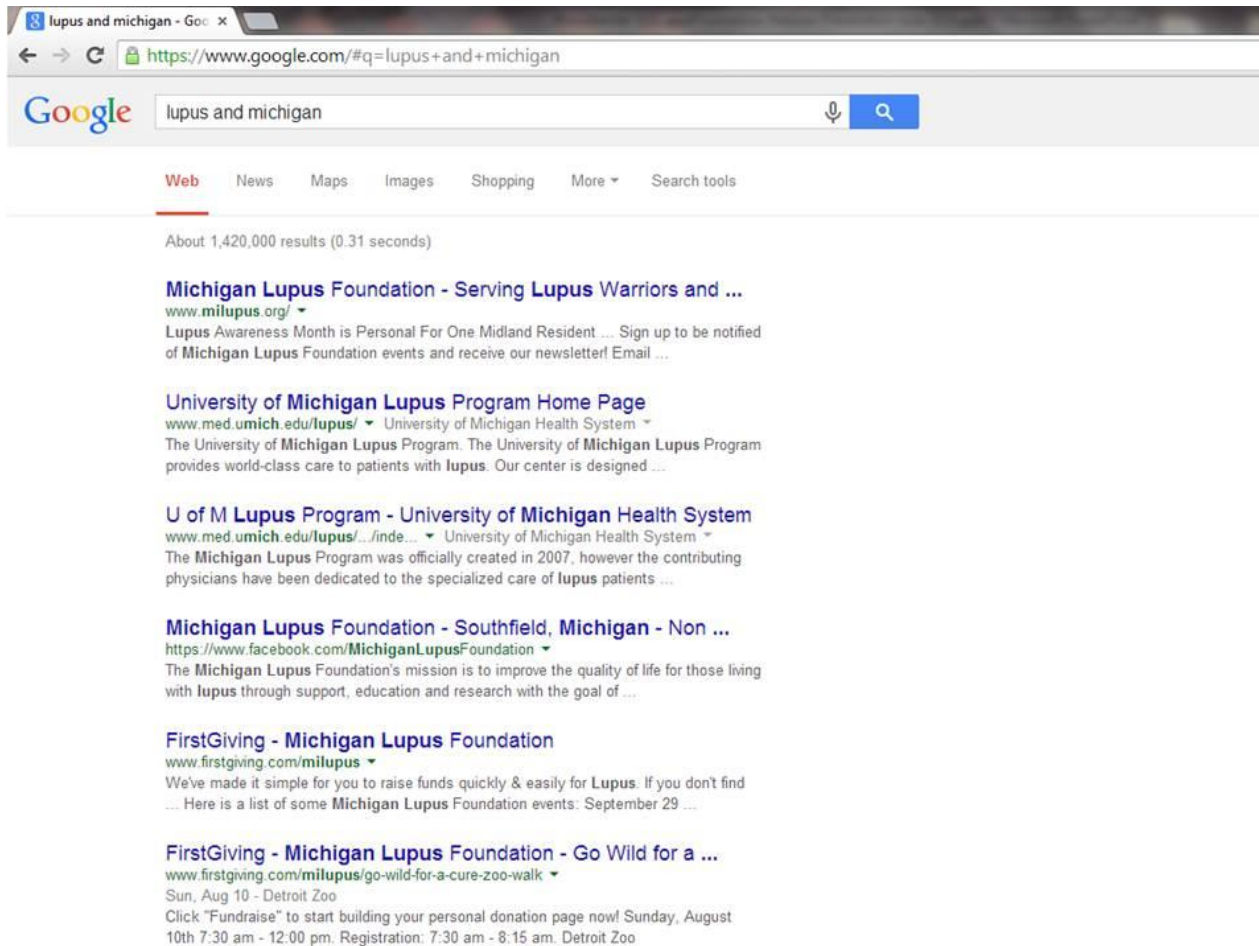
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# Resources




lupus and michigan - Google



https://www.google.com/#q=lupus+and+michigan



Google lupus and michigan


Web News Maps Images Shopping More Search tools


About 1,420,000 results (0.31 seconds)


**Michigan Lupus Foundation - Serving Lupus Warriors and ...**  
www.milupus.org/   
Lupus Awareness Month is Personal For One Midland Resident ... Sign up to be notified of Michigan Lupus Foundation events and receive our newsletter! Email ...

**University of Michigan Lupus Program Home Page**  
www.med.umich.edu/lupus/  University of Michigan Health System   
The University of Michigan Lupus Program. The University of Michigan Lupus Program provides world-class care to patients with lupus. Our center is designed ...

**U of M Lupus Program - University of Michigan Health System**  
www.med.umich.edu/lupus/.../inde...  University of Michigan Health System   
The Michigan Lupus Program was officially created in 2007, however the contributing physicians have been dedicated to the specialized care of lupus patients ...

**Michigan Lupus Foundation - Southfield, Michigan - Non ...**  
https://www.facebook.com/MichiganLupusFoundation   
The Michigan Lupus Foundation's mission is to improve the quality of life for those living with lupus through support, education and research with the goal of ...

**FirstGiving - Michigan Lupus Foundation**  
www.firstgiving.com/milupus   
We've made it simple for you to raise funds quickly & easily for Lupus. If you don't find ... Here is a list of some Michigan Lupus Foundation events: September 29 ...

**FirstGiving - Michigan Lupus Foundation - Go Wild for a ...**  
www.firstgiving.com/milupus/go-wild-for-a-cure-zoo-walk   
Sun, Aug 10 - Detroit Zoo  
Click "Fundraise" to start building your personal donation page now! Sunday, August 10th 7:30 am - 12:00 pm. Registration: 7:30 am - 8:15 am. Detroit Zoo

# Resources

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- Jessica's Coping with Lupus Corner

<http://lupusny.org/about-lupus/coping-with-lupus-corner>

- [Coping Toolkit for the New Year](#)
- [Taking Care of Your Body Overall](#)
- [Good Patient](#)
- [Consider Your Relationship with Your Doctor](#)
- [Giving Thanks Gives a Health Boost](#)
- [Wash Your Hands of Self-Criticism](#)
- [Being Prepared for a Lupus Flare](#)
- [Humor](#)
- [Lupus through the Lens](#)



# Resources

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- S.L.E. Lupus Foundation webinar archive

<http://lupusny.org/programs/support-services/lupus-webinar-archive>

- S.L.E. Lupus Foundation YouTube videos

<http://www.youtube.com/user/LupusNY>

# The S.L.E. Lupus Foundation - Services

- New York City Support Services
  - Support groups
  - Crisis intervention & short term counseling
  - Benefits/entitlements
  - Grants for adults and children
  - Information and referral services, doctors/specialists
  - Summer camp for children and their families
- Education
  - Patients
  - Health care professionals



# The S.L.E. Lupus Foundation - Services

- Public Awareness
  - Presentations
  - Outreach
  - Materials
- LCNy – Lupus Cooperative of NY
- Research
  - Novel research in NYC
  - Nationally, Lupus Research Institute (LRI)



# The S.L.E. Lupus Foundation - Services

- Advocacy
  - NYC
  - Statewide with Lupus Agencies of NYS
  - National with Lupus Research Institute National Coalition



# The S.L.E. Lupus Foundation

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- Visit [www.lupusny.org](http://www.lupusny.org) for more on our programs and general information about lupus
- For the latest in lupus research go to [www.lupusresearchinstitute.org](http://www.lupusresearchinstitute.org)
- To participate in research, visit [www.lupustrials.org](http://www.lupustrials.org)
- **Follow us! Twitter.com/LupusNY**
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Questions?