


LUPUS ONTARIO
Life Without Lupus

For Teens With Lupus


Lupus Ontario Rev. 2018-09-22 Support and Education Committee



I Have Lupus

- You might be asking yourself:
 - What is lupus anyway?
 - An autoimmune disease.
 - Is it contagious?
 - No.
 - What’s lupus got to do with anything?
 - Fatigue, totally exhaustion
 - Pain, stiffness, swelling
 - Rashes
 - Hair Loss
 - Brain fog, trouble thinking or speaking, memory lapses


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I Have Lupus

- Not everyone gets all kinds of symptoms. It is different for everyone which is why it is called the disease of a thousand faces.
- Lupus is a disease you cannot see on the outside most of the time.
- You may not want anyone to know your diagnosis. Ask people to please respect your right to privacy and ask them to be supportive of you in any way they can.


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The Road to Diagnosis

- Sometimes you don’t feel well for a long time before you get a diagnosis.
- This can be frustrating, cause fears of the unknown, be depressing, or make you feel anxious.
- You are entitled to your feelings.
- Feelings about your health and wellness are important to acknowledge.


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The Road to Diagnosis

- Thoughts and feelings help you to know when you are feeling that it is too much to handle on your own.
- This is the time to ask for and accept help, including psychological help which could be just talking to a trusted friend, a counselor or therapist, a spiritual director, your doctor or a trusted family member. Writing down your thoughts and feelings in a journal can help.

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Dx Lupus, What’s Next

- So, I have a diagnosis of lupus, now what?
- Learn about what lupus is and what it isn’t.
- Educate yourself about your medications and potential side effects, body and energy work.
- Learn about what you can do to help yourself.
- Join a support group, either face to face or online.

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What is Lupus?

- Lupus is an autoimmune disease meaning that your body makes antibodies against itself in any cell, tissue or organ in your body.
- Inflammation, pain and fatigue are common as are skin rashes, hair falling out, or lots of side effects from the medications.
- Think of the worst day you have had with the flu and multiply it by 100. That's how you can feel sometimes or most of the time.

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Visible Symptoms

- Skin rashes, sores, stiff movements
- Frequent washroom trips for nausea or diarrhea
- Hair loss in patches, general thinning or a lot sometimes
- Mood swings, depression, anxiety
- Redness, swelling
- People can make cruel comments about a person's appearance. Try not to take it personally. It can hurt your feelings and make you sad, angry or hopeless.

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Choices After Diagnosis

- Eat whole foods and drink enough clean water.
 - Limit sugar, hydrogenated fats, refined carbohydrates and grains (white bread/pasta), salt, caffeine, alcohol, artificial flavour/colour/preservatives, foods raised with hormones or antibiotics.
 - Choose certified organic as much as possible.
 - Eat whole grains, nuts, seeds, legumes, lentils, vegetables, fruit, lean protein, and omega 3-6-9 containing foods.
- Get daily exercise, even if just walking.
- Learn relaxation techniques, deep breathing, breathing to a count, creative visualization and mindfulness.
- Investigate body and energy therapies that may help your symptoms.

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Choices After Diagnosis

- Body therapies will depend on your symptoms
 - Nutrition
 - Osteopathic Treatments or Chiropractic
 - Physiotherapy, Massage, Hydrotherapy
 - Laser, TENS, Acupressure, Reflexology, etc.
 - Exercise, perhaps a personal trainer/fitness coach, yoga, tai chi, aquafitness
 - Occupational Therapy
 - Other naturopathic modalities

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Choices After Diagnosis

- Energy therapies that may help symptoms
 - Acupuncture
 - Reiki, Therapeutic Touch, Touch for Health
 - Spiritual Kinesiology
 - Emotional Intelligence
 - Qi Gong, Tai Chi, Chakra Balancing
 - Music Therapy, Garden Therapy
 - Homeopathic Medicine, Ayurvedic Medicine
 - Traditional Chinese Medicine

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Choices After Diagnosis

- Pacing and Priorities
 - You have new limitations on your energy from fatigue or pain, medication side effects, stress, etc.
 - Learn how much you can do in a day without making your symptoms worse.
 - Accepting your new limits makes it less stressful for you and you may have to explain this to family and friends. Ask for their support not criticism.
 - Prioritize your to do list based on what actually has to be done instead of what you want to do.

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Choices After Diagnosis

- Practice Good Sleep Hygiene
 - Get enough sleep, 6-8 hours per night.
 - Go to bed at the same time every night.
 - No electronics in the bedroom, yes it is important because the electromagnetic fields and blue light affect your lupus and your sleep.
 - No heavy exercise 1 hour before bed.
 - No snacks 1 hour before bed.
 - Consult a sleep specialist if necessary.

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How Does It Affect Me

- You may be too tired or in too much pain to do things you have planned to do.
- You may have to cancel important social events, school or work with no notice.
- Sunlight and indoor lights may make you very sick. Sunscreen, sun protective clothing, hats and sunglasses may not be a fashion statement but they are essential to keep from getting even more sick.

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How Does It Affect Me

- Fatigue or pain may make it hard for you to concentrate at school or work. You might need extra time for tests, exams, homework or projects.
- Symptoms may interfere with your focus or memory.
- Symptoms may interfere with vision, reading, driving and computer work.

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Coping

- Having a chronic illness can be stressful.
- Finding people you trust to talk to, including professionals, can give you an outlet for fears, accomplishments, treatment success, anxiety, depression or just a need to unload it all.
 - OHIP therapists, counselors, psychologists, either individual or group, social worker, etc.
 - Private insurance therapist, counselors, groups.
 - Support Groups, face to face and online.

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Your Teams

- Your treatment and support teams will be made up of a variety of different professions.
 - Medical doctors, nurses, holistic nutritionist, physiotherapist, fitness coach, family, friends, support group members, counselor, osteopath, rheumatologist, etc.
 - Make a list of who is on your treatment team and who is on your support team today, and then list who else you would like on your teams. Ask for help to connect with those people.

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Your Appearance

- Lupus can affect your:
 - Skin
 - Hair
 - Weight – gain or loss
 - Fitness level, muscle tone, muscle strength
 - Eyes- dry eyes may need artificial tears
 - Mouth - may need a lubricant like biotene
 - Self image and confidence

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Your Skin

- Your skin may have rashes, sores or dryness that a dermatologist, cosmetologist or make up artist can help you with.
 - 100% natural, chemical and scent free, organic products can help a lot and includes shampoo, conditioner, hair gel, deodorant, skin cream or lotion, toothpaste, mouth wash and any other product you put on your skin.
 - All are available in pharmacies, health food stores, grocery stores and online.

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Your Hair

- Lupus can cause changes in the colour or texture of your hair. Sometimes hair can fall out in clumps or thin.
 - Your hair stylist can help with finding a style that covers up problem areas, or with hair pieces or wigs in extreme cases. 100% natural hair products can help.
 - Your doctor can help with scalp treatments and identifying any nutritional deficiencies that affect your hair and scalp.

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Your Body Shape

- Lupus or the medications can cause changes in weight and muscle tone.
 - Medications like prednisone make you feel hungry so it is easy to overeat and gain weight. Other medications may cause you to lose weight.
 - Your holistic nutritionist or dietician can help with identifying any nutritional deficiencies and help you transition to a more whole foods diet.
 - Positive mental attitude is key to accepting and managing changes in your appearance.

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Possible Issues

- Cancelling plans at the last minute.
- Missing school or work.
- Missing sports, concerts, dates, etc.
- Physical changes in hair, skin and body, and learning how to manage them.
- Fatigue, pain, nausea, diarrhea.
- Memory problems, word finding, wayfinding.
- Other symptoms.

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Solutions

- Educate yourself about lupus and treatments.
- Ask for and accept help.
- Participate in a support group. They are living with lupus too and sharing what works can help a lot.
- Stay active, both mentally and physically within the limits your symptoms give you.
- Pacing and priorities (again, super important)


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For Teachers and Employers


- Educate yourself about lupus and treatments.
- Ask your students what they need.**
- Acknowledge their symptoms and affirm them in their attempts to follow their treatment and cope.
- Read "Lupus Etiquette for People Who Don't Have Lupus" at <https://www.healthy4life.ca/lupus.html>

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- Refer them to additional resources in their school, your local school board and the community.
- Remember they have rights as a person with a disability of chronic illness.
 - They may need physical accommodation, vision adaptive technology, assistive technology for hearing changes and course material adaptable to fluctuating cognitive function.

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LUPUS ONTARIO  **Resources**


- **Lupus**
 - www.lupusontario.org
 - <http://www.lupusontario.org/wp-content/uploads/2017/12/living-well-with-lupus.pdf>
 - <https://www.lupuscanada.org/government-support-programs/>
 - <https://www.mayoclinic.org/diseases-conditions/lupus/symptoms-causes/syc-20365789webmd>
 - <https://www.webmd.com/lupus/guide/lupus-overview-facts>

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LUPUS ONTARIO  **Resources**

- **Nutrition**
 - <https://www.healthy4life.ca/lupus.html>
 - <https://www.health.harvard.edu/staying-healthy/foods-that-fight-inflammation>
 - <https://www.ewg.org/foodnews/clean-fifteen.php>
 - <https://www.ewg.org/foodnews/dirty-dozen.php>
 - <https://www.webmd.com/diet/anti-inflammatory-diet-road-to-good-health#1>
 - <https://nutritiondata.self.com/>

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LUPUS ONTARIO  **Questions?**

- If you have any questions or would like more information, you can contact Lupus Ontario at 1-877-240-1099 or 905-415-1099
- Or one of the members of the Support & Education Committee:
 - Tarra tarraandjedmarvin11@gmail.com
 - Cathy cathyferrenrh@gmail.com
 - Juanita jbutler@lupusontario.org

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