

**LUPUS**  
**ONTARIO**  
Life Without Lupus



# **For Friends of Teens With Lupus**

# My Friend Has 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

# My Friend Has 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.
- Your friend may not want anyone to know the diagnosis. Please respect your friend's right to privacy and be supportive any way you can. It means a lot.

# What is Lupus?

- Lupus is an autoimmune disease meaning the body makes antibodies against itself in any cell, tissue or organ in the 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 your friend can feel sometimes or most of the time.

# Visible Symptoms

- Skin rashes, sores
- Frequent washroom trips for nausea or diarrhea
- Hair loss in patches, general thinning or a lot sometimes
- Mood swings, depression, anxiety
- Redness, swelling
- Stiff movements
- People can make cruel comments about a person's appearance. Try not to be one of them.

# How Does It Affect Me

- Your friend may be too tired or in too much pain to do things you have planned to do.
- Your friend may have to cancel important social events, school or work with no notice.
- Sunlight and indoor lights may make your friend 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.

# What Can I Do

- Try to be kind and compassionate, instead of teasing the person about special clothing, wear something similar yourself.
- Know that sometimes your friend will have to cancel going out to movies, shopping, sports events, family gatherings, study groups, or any other activity on a bad day. It's not that they don't want to, they are just physically not able to do things. Be flexible about rescheduling.

# What Can I Do

- Try to be aware of when your friend is not feeling well just by how they move, how fast they move, if they are having trouble speaking or get lost going someplace you always go to.
- Keep in touch, by phone, text, instagram, facebook, whatever you would normally do.
- Don't focus your conversations on their symptoms. Your friend wants to be as normal as possible in spite of having lupus.



# What Can I Do

- When other people give your friend a hard time just because they are sick, stand up for them.
  - Don't let people bully them. You would want your friend to do the same for you.
  - Offer to help with a task when other people cannot overhear. There are lots of ways to help without being obvious.
  - Just being there and not treating them like a freak helps more than you can know.

# What Can I Do

- When a person is in a lot of pain or super nauseated it can be hard to be pleasant.
  - Hormones, thoughts and feelings are all affected by the disease and the treatments.
  - More than anything, don't take it personally if the person is moody or says hurtful things. It does not mean they have the right to treat you badly, however, they really are not themselves. Having a friend to talk to can help, especially if you can listen without judgement.

# What Can I Do

- Your friend has lupus.
- You may have questions, concerns or fears.
- Learn what you feel comfortable with about the disease and talk to people you trust. It might be your parents, a friend, a spiritual director, a counsellor, any person who you know will keep your conversation confidential.
- Your friend is still your friend, just with a few new limitations when their lupus flares up.

# 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](mailto:tarraandjedmarvin11@gmail.com)
- Cathy [cathyferrenrhn@gmail.com](mailto:cathyferrenrhn@gmail.com)
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