

LUPUS
ONTARIO
Life Without Lupus



For Teachers of Teens With Lupus

My Student 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 my student?
 - Fatigue, totally exhaustion
 - Pain, stiffness, swelling, Rashes
 - Hair Loss, swollen face, hands or whole body
 - Brain fog, trouble thinking or speaking, memory lapses

What is 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 student may not want anyone to know their diagnosis. Ask people to please respect their right to privacy and ask them to be supportive of them in any way they can.

What is Lupus?

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

How Lupus Can Affect School

- Physical changes make the lupus student subject to negative comments, teasing and bullying.
- Chronic pain and/or chronic fatigue can affect their ability to focus in class, on homework, or during tests and exams.
- Muscle stiffness or weakness affects their ability to move around.

How Lupus Can Affect School

- Nausea, vomiting, diarrhea, profuse sweating, or extreme chills can also affect their classroom focus as well as their ability to do sports.
- Cognitive challenges can include the inability to concentrate, word finding and way finding problems, short and medium term memory lapses, the inability to get restorative sleep, and many others.

Social Challenges

- Self esteem can be lowered by changes in body weight, hair loss, skin rashes due to either the disease itself or from medications and other treatments used.
- Lupus students often have to cancel sports activities or social events at the last minute. Often friends and family don't understand this and may accuse them of being lazy or just not caring about the other person.

Social Challenges

- Being excluded from social activities can lead to isolation and loneliness.
- Dating can be a challenge due to the unpredictability of symptoms, fatigue, pain, body changes, people's ignorance and misconceptions about the disease.
- Fear, anxiety and depression are not uncommon.

Social Challenges

- Fear of rejection causes many students with lupus to hide their symptoms or not tell their friends, family or teachers about their lupus. With cancer, everyone has some idea what it is and readily accept a person's limitations.
- The student with lupus can receive a lot of criticism and negative comments about their visible symptoms, their altered mental status or their extreme fatigue.

School Adaptations

- A student with lupus deserves the same accommodations as any other person with a chronic illness.
- This might include: large print handouts or text books; audible handouts or text books; scalable font computer resources; longer time to complete assignments, texts or exams; being excused from physical activities depending on their symptoms; being listened to and believed.

School Help

- If the student has advised the school that they have lupus, it is important that the staff who deal with the student educate themselves on lupus and how it affects their particular student.
- Mental health resources are important to living with and coping with lupus. The student will need access to a caring and supportive guidance counselor or school therapist.

School Help

- Medication compliance, good nutrition, stress management, adequate rest and positive life skills are all key to your student living well with lupus.
- Lupus education can be a part of the regular health education classes at your school, particularly during the lessons on autoimmune disease.

School Help

- Lupus Ontario has a number of presentations to help including ‘For Teens With Lupus’ and ‘For Friends of Teens With Lupus’ in addition to this one ‘For Teachers of Teens With Lupus’.
- These are posted on the Lupus Ontario web site ‘Education Page’ under the section ‘Living With Lupus’.
- <http://www.lupusontario.org/living-with-lupus/education/>

Lupus Ontario

- Depending on the availability of our volunteers, Lupus Ontario may be able to provide you a volunteer to come to your school in person or through an online Zoom meeting to answer questions you may have or to give a presentation to the teachers/staff or to the students.
- Contact the Lupus Ontario Support and Education Committee through the office at 1-877-240-1099

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:
- Cathy cathyferrenrhn@gmail.com
- Tarra tarraandjedmarvin11@gmail.com
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