

HOPE

life without lupus

[#LetsTalkLupus](#)

[#MakeLupusVisible](#)

WHO IS LUPUS CANADA?

Lupus Canada is the only national organization focused on lupus research, advocacy, awareness and education in Canada

No other organization provides a bigger opportunity to make an impact on lupus and those who live with it.

We are fiercely committed to improving the lives of people living with lupus, their families, and their loved ones by investing in the initiatives that bring us closer to dedicated treatments and, ultimately, a cure.

Lupus Canada is run by a talented, diverse, volunteer group of Board of Directors and 3 full time employees.

WHAT IS LUPUS?

*Imagine being in a constant state of fatigue
with flu-like symptoms*

This is lupus!

WHAT IS LUPUS?

- Lupus is a chronic, autoimmune disease that can damage **any organ** in the body, in **any individual**, at **any point in their lives**. The cause remains unknown, and a cure does not exist.
- Over **1 to 1,000** Canadian men, women and children live with lupus.
- **80%** of patients develop lupus between **15 and 44** years of age (***primary working years***).
- Given it can take **up to 7 years** for diagnosis patients are left without proper treatments which adversely impacts their overall health.
- Disease can range from mild to **life threatening**.
- **90%** of lupus patients are women but we are seeing more men and children being diagnosed.

LUPUS SYMPTOMS

The list of symptoms lupus patients experience is staggering



LUPUS – HOW IT IMPACTS WORK AND DAILY LIFE

47.7%

of family members had to take time off work to help care for their loved one living with lupus

23%

had to be away from work for more than 25 days due to lupus

35.5%

experience 1 to 3 flares in 12 months

44%

lupus impacted their daily life, including the ability to care for themselves or their family

LUPUS – THE EMOTIONAL IMPACT

People's journey with lupus was one full of ups and downs, often laced with uncertainty and frustration.

Frustration. Before a diagnosis was established, patients were often labelled hypochondriacs, lazy, or just tired by their family and GPs. Patients felt frustrated, misunderstood, and mislabelled.

Unhelpful GPs. Patients who were diagnosed by their GPs complained about a lack of empathy and disease knowledge. They expected an expert who could tell them exactly what was wrong.

Running around to specialists. They felt they were waiting for appointments for specialists and being tossed around the healthcare system until a firm diagnosis was made.

Lack of effective treatment. Once diagnosed, patients were often told that the treatment they were on may or may not work. There was a perception that lupus does not get enough attention in research and drug development despite a lack of treatments.

LUPUS – THE EMOTIONAL IMPACT

Patients with lupus face a large emotional burden due to the chronic nature of their disease.

Anxiety and Depression. Most physicians mentioned an underlying depression in their patients because of the chronic nature of lupus.

Worry. Often patients “complain” to the rheumatologist about pains and concerns. Due to the amorphous characteristic of the disease, they worry everything new is their lupus becoming active.

Uncertainty. Unlike rheumatoid arthritis where some level of disease progression can be expected, lupus is unpredictable and patients must deal with the uncertainty of their prognosis.



THE DISEASE OF 1000 FACES

LUPUS
CANADA
Life Without Lupus



“How much lupus impacts our day to day, even if we look fine on the outside, we’re probably not feeling well at all making it difficult to do the simplest of tasks. And no, there is no cure....”

“I am no longer the person I was pre-lupus and taking the time to be kind to myself requires a lot of work and patience.”

“Even if you don’t see the symptoms, it doesn’t mean that we’re not sick, Pain is really real and very hard to manage even with the proper medication.”

“I feel guilty about all the things I can’t do all the time. Especially housework and not having the energy to engage with my children in physical activities.”

“Even though it is invisible to most people, it is constantly exhausting and painful. Also, a chronic disease plays a large role in your mental health.”

“Even though we wake up every day wanting to not feel any pain and be productive we simply can’t. And also, we might get better at handling our disease with time but that doesn’t mean that it’s gone, or it no longer impacts negatively our quality of life.”

“Lupus flares may happen at any time and may negatively impact our life and our ability to perform work or daily activities which is not within our control. One cannot easily tell if a person is living with this autoimmune disease as lupus is an invisible illness that can attack your body from the inside in many different ways or forms.”

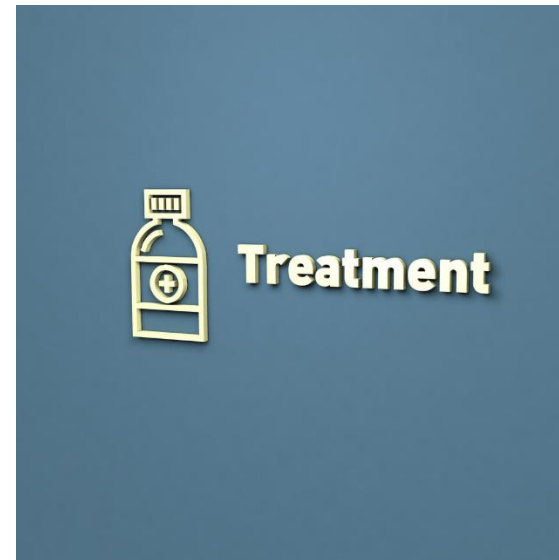
“Having workplace benefits for medications has been a godsend. If I didn't have workplace benefits I wouldn't be able to afford my medications..”

“I have workplace benefits that include things like physiotherapists, psychologists, massage therapy etc. These benefits help me greatly both with my mental health and depression related to having a chronic debilitating condition like lupus, and my physical health, as lupus damages my muscles and joints.”

Lupus Treatments

Limited Treatment for lupus. Most lupus patients are on a cocktail of medications to manage their disease that were not originally developed to treat lupus.

Adverse long-term effects. Prolonged treatments used to manage lupus such as Prednisone and Corticosteroids can have adverse long-term effects, including potential bone loss and osteoporosis, excessive weight gain and fluid retention.



Lupus Treatments

- With no new lupus specific medicines in over 60 years, **new innovative therapies** on the horizon brings **hope** to those impacted by lupus.
- All Canadian lupus patients should have **easy and equitable access to lupus specific drugs**.
- Delays to access for patients can be detrimental to their health and therefore **drug reviews need to be conducted in a timely manner**.
- Coverage and access to treatment is critical to ensure Canadians living with lupus are able to **maintain productivity**.
- New innovative treatments may help **reduce duration on disability**.

How Employers Can Help

- Provide accommodations for those living with lupus, such as working from home, allow for flexible break/lunch times etc.
- Provide comprehensive benefits to support patient care. (ie. provide access to medications and alternate treatment options such as physiotherapy, chiropractic care, psychologists etc.)
- Flexibility and understanding about medical appointments.
- Provide additional sick days to allow for recovery time following flares.
- Be mindful that UV lighting can be harmful.
- Improved communication and understanding of HR policies.
- Provide an employee wellness program which will improve the health and productivity of employees and potentially improve the overall cost of employer-provided health care.

