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Lesson 3 – Treatment options and shared decision-making

In Lessons 1 and 2, we explored what lupus is, how it affects the body, and how doctors or specialists diagnose and monitor the disease. Once lupus has been diagnosed, the next step is developing a treatment plan that reflects your symptoms, disease activity, lifestyle, and personal goals.

Lupus treatment has improved significantly over the past two decades. Earlier diagnosis, better monitoring, and new treatment options are helping many people achieve improved disease control and quality of life. While there is currently no cure for lupus, effective treatment can help reduce inflammation, control symptoms, prevent flares, protect organs from damage, and help people maintain their daily activities and long-term health.

Treatment decisions can sometimes feel overwhelming. Understanding the goals of treatment, how medications work, and what questions to ask can help you become a more informed and confident partner in your care.

Please note that there are several forms of lupus, but the most common and serious form is **systemic lupus erythematosus (SLE)**. When people use the term “lupus”, they are usually referring to SLE. This Course focuses primarily on SLE, which is most often associated with arthritis, flares, and involvement of organs such as the kidneys, heart, lungs, and brain.

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Why This Matters

Understanding your treatment options can help you feel more confident discussing medications, asking questions, recognizing side effects, and making informed decisions with your healthcare team.

Treatment works best when you understand its goals and actively participate in your care.

Feel more confident
Understanding your options helps you feel more in control

Discuss medications
Be prepared to talk with your healthcare team about what's right for you

Ask questions
Get the answers you need to make informed choices about your treatment

Recognize side effects
Knowing what to watch for helps you stay safe and speak up early

Actively participate
You are an important partner in your care and treatment journey

When you understand your treatment, you are better equipped to achieve your treatment goals and live well with lupus.

Treatment goals in lupus

The primary goals of lupus treatment are to:

- Reduce inflammation and disease activity
- Control symptoms such as pain, fatigue, rashes, and joint swelling
- Prevent flares
- Protect organs from damage
- Reduce medication-related side effects
- Maintain physical function and quality of life
- Support long-term health and wellbeing

Treatment plans vary because lupus affects each person differently. Modern lupus care increasingly focuses on achieving low disease activity or remission whenever possible while minimizing treatment-related risks. Disease activity refers to how active lupus is in your body at a given time. Remission means lupus is quiet and causing few or no symptoms.

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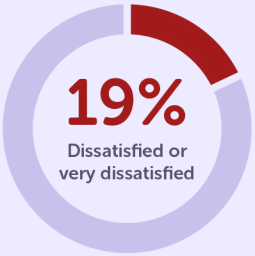
What People with Lupus Told Us

Arthritis Consumer Experts' National Survey on Lupus in Canada found that while most people were generally satisfied with their current treatment, important gaps remain.

Nearly two-thirds (64%) reported being satisfied or very satisfied with their lupus treatment.



Almost one in five (19%) reported being dissatisfied or very dissatisfied.

These findings suggest that although current therapies are helping many people manage their disease, some patients continue to experience unmet treatment needs, ongoing symptoms, side effects, or barriers to optimal care.

Your experience matter. Sharing your voice helps improve care and supports the lupus community.

Understanding lupus medications

Lupus treatment is about more than controlling symptoms. The goal is also to prevent long-term damage to organs such as the kidneys, heart, lungs, and brain.

Long-term disease control

Hydroxychloroquine is considered a cornerstone treatment for most people living with systemic lupus erythematosus (SLE). Originally developed to treat malaria, hydroxychloroquine helps regulate the immune system and reduce inflammation.

Research has shown that hydroxychloroquine can:

- Reduce disease activity
- Lower the risk of flares
- Help protect organs from damage
- Improve long-term outcomes
- Reduce the need for corticosteroids
- Because of these benefits, lupus experts generally recommend hydroxychloroquine for most patients unless there is a specific reason it cannot be used.

Regular eye examinations are important because rare retinal side effects can occur with long-term use. Your health care provider will recommend appropriate eye monitoring.

Inflammation reduction during flares

Corticosteroids such as prednisone are powerful anti-inflammatory medications.

They can be highly effective at controlling inflammation and managing flares quickly. However, long-term steroid use may increase the risk of:

- Weight gain
- Osteoporosis
- Diabetes
- High blood pressure
- Cataracts
- Increased infection risk
- Mood changes

Current lupus treatment guidelines emphasize using the lowest effective steroid dose for the shortest possible time.

Many newer treatment strategies focus on reducing dependence on long-term corticosteroid therapy whenever possible.

Remember

Corticosteroids can be very effective, especially during flares. Because long-term use may cause side effects, health care providers try to use the lowest effective dose for the shortest possible time.

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Controlling moderate to severe lupus

Some people require immunosuppressive medications that suppress immune system activity more directly. These medications may be used when lupus affects major organs such as the kidneys, or when disease activity is not adequately controlled with other therapies.

Examples include:

- Azathioprine
- Methotrexate
- Mycophenolate mofetil
- Cyclophosphamide

These medications can be very effective, but they also require regular monitoring because they may affect blood counts, liver function, or infection risk.

Your doctor or specialist will explain the benefits and risks of each medication and the monitoring that is required.

Newer targeted therapies

In recent years, advances in lupus research have led to the development of targeted biologic therapies. Biologic medications are newer treatments designed to target specific parts of the immune system involved in lupus.

Examples include:

- Belimumab
- Anifrolumab

These therapies may be considered when disease activity remains uncontrolled despite standard treatments or when steroid-sparing approaches are needed.

Not everyone with lupus requires biologic therapy. However, these treatments represent important progress and provide additional options for patients whose disease remains active despite conventional treatment.

Researchers continue to investigate new therapies that may further improve outcomes and reduce treatment-related side effects.

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Access to medications and reimbursement

Advances in lupus treatment have improved outcomes for many people. But receiving a prescription is only one step in accessing treatment. Patients must also be able to obtain the medication, afford it, and maintain access over time.

In Canada, medication coverage varies depending on where a person lives, the type of insurance they have, and the medication prescribed. Some medications are covered through public drug plans, some through private insurance plans, and others may require special authorization before reimbursement is approved.

For people living with lupus, uncertainty about medication coverage can be stressful. Delays in reimbursement decisions, out-of-pocket costs, and changing insurance requirements can create additional challenges when managing a chronic disease.

When access barriers occur, patients may benefit from speaking with their healthcare team, patient support programs, pharmacists, or insurance providers to better understand available options and resources.

What People with Lupus Told Us

Access to treatment remains a challenge for some Canadians living with lupus.

Survey findings suggest that financial barriers and inconsistent coverage continue to prevent some patients from receiving optimal treatment, even when effective therapies are available.

In ACE's National Survey on Lupus in Canada, 57% of people reported that accessing reimbursement for prescribed lupus medications was easy or very easy.

However, 12% described the process as difficult or very difficult.

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Medication safety and monitoring

Every medication has potential benefits and risks. Health care providers carefully balance these considerations when recommending treatment.

Important aspects of medication safety include:

- Attending regular appointments
- Completing recommended blood and urine testing
- Reporting side effects promptly
- Discussing vaccinations
- Informing health care providers about other medications and supplements
- Following recommended monitoring schedules

Never stop or change a medication without first discussing it with your healthcare team.

If you have concerns about side effects, effectiveness, or safety, bring those concerns forward. Many treatment challenges can be addressed through open communication.

Staying on track with your medications

Medication adherence means staying on track and taking medications as prescribed. This can be challenging when symptoms improve, medications cause side effects, or treatment routines become complicated. But stopping medications without medical guidance may increase the risk of disease flares and long-term complications. If you are having difficulty taking your medications, speak with your healthcare team rather than stopping them on your own.

Strategies that may help include:

- Using pill organizers
- Setting reminders
- Linking medications to daily routines
- Asking questions about treatment goals
- Discussing side effects early
- Understanding how each medication contributes to disease control

Knowing why a medication has been prescribed often makes it easier to remain engaged with treatment over time.

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Shared decision-making

Shared decision-making means patients and health care providers work together when making treatment decisions. Shared decision-making recognizes that you are the expert on how lupus affects your daily life, while your healthcare team brings expertise about diagnosis and treatment. Working together leads to better decisions.

Rather than simply being told what to do, patients are encouraged to:

- Ask questions
- Share concerns
- Discuss personal goals
- Consider treatment benefits and risks
- Express preferences and values

Shared decision-making recognizes that patients are experts in their own experiences and that treatment decisions should reflect both medical evidence and individual priorities.

Questions for your doctor or specialist:

- What is this medication intended to do? Why is it recommended for me?
- What side effects should I watch for?
- How will we know if treatment is working? What benefits should I expect?
- Are there alternative options?
- What monitoring is required?
- How long will it take before this medication starts working?
- What are the risks of not treating my lupus?
- What happens if this medication doesn't work?
- Are there lifestyle changes that can help alongside my medications?

These conversations can help build trust, improve understanding, and support treatment decisions that align with your goals and values.

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Important Learning Points from Lesson 3

1. **The goals of lupus treatment** are to reduce inflammation, control symptoms, prevent flares, and protect organs from damage.
2. **Treatment plans are individualized** and depend on disease severity, symptoms, and which organs are affected.
3. **Understanding the benefits and risks of medications** can help support informed treatment decisions and long-term adherence.
4. **Shared decision-making** between patients and health care providers is an important part of achieving the best possible outcomes.

Looking Ahead to the Next Lesson

Medication is only one part of living well with lupus. Daily habits and self-management strategies can also help you manage symptoms, maintain your physical and emotional wellbeing, and stay active in the activities that matter most to you.

In the next lesson, we'll explore practical strategies for managing fatigue, protecting your mental health, staying physically active, and living well with lupus.

Small steps today can lead to big improvements in your quality of life tomorrow.

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