JHEd Lupus

Lesson 4 – Living well with lupus

In the first three lessons, we explored what lupus is, how it is diagnosed and monitored, and the treatments used to control disease activity and prevent organ damage.

Living well with lupus involves much more than managing laboratory test results and medications. Many people living with lupus face challenges that affect their daily lives, including fatigue, pain, sleep difficulties, stress, anxiety, depression, and physical activity limitations.

The good news is that there are practical strategies that can help you manage symptoms, protect your health, maintain independence, and improve quality of life.

In this lesson, we explore common day-to-day challenges experienced by people living with lupus and discuss practical approaches that can help you live well with the disease.

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.

Why This Matters

Lupus affects more than the immune system. It can influence how you feel physically, emotionally, socially, and mentally. Symptoms such as fatigue, pain, brain fog (thinking and memory difficulties), anxiety, and sleep disturbances can make everyday activities more difficult and unpredictable.

Understanding practical self-management strategies can help you better manage symptoms, maintain independence, improve quality of life, and feel more confident living with lupus.

Manage symptoms
Practical strategies can help reduce symptoms and day-to-day challenges.

Maintain independence
Build confidence and stay in control of your life.

Improve quality of life
Feel better physically, emotionally, and socially.

Support mental wellbeing
Address the emotional impact and build resilience.

Live more confidently
Be prepared, plan ahead, and handle the unexpected.

You are not alone. With the right tools and support you can live well with lupus — every day.

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Fatigue and lupus

Many people living with lupus identify fatigue as one of the most difficult symptoms to manage. Some people report that fatigue has a greater impact on their daily lives than pain, skin symptoms, or other symptoms that people can easily see.

Lupus fatigue is very different from ordinary tiredness. It is not simply the result of a busy day or a poor night's sleep. Many people describe it as a deep physical and mental exhaustion that can make even simple activities feel overwhelming.

Fatigue can affect many aspects of life, including:

- Work and career responsibilities
- Parenting and caregiving activities
- Household tasks and errands
- Physical activity and exercise
- Social activities and relationships
- Concentration and decision-making

Because fatigue is invisible, it can sometimes be difficult for family members, friends, coworkers, and employers to understand. Many people with lupus report feeling frustrated when others assume they are "just tired" or should be able to push through their symptoms.

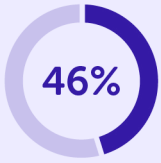
There is rarely a single cause of lupus fatigue. Disease activity, pain, poor sleep, medications, stress, anxiety, depression, and other health conditions can all contribute.

Learning to recognize your fatigue patterns and manage your energy wisely is an important self-management skill. Although fatigue cannot always be eliminated, many people find that following their treatment plan and keeping their lupus well controlled, staying physically active, pacing their activities, and having healthy sleep habits help reduce its impact.

What People with Lupus Told Us

Fatigue is not simply a minor symptom of lupus. For many people, it is one of the most significant challenges they face.

The impact of fatigue was one of the strongest themes identified in ACE's National Survey on Lupus in Canada.



Nearly half of the people who took the survey **(46%)** reported that lupus affects their ability to participate in physical activity.

Another **36%** reported that it sometimes affects physical activity.

People described fatigue as affecting:

- Their ability to exercise
- Family activities
- Work productivity
- Social participation
- Household responsibilities
- Overall quality of life

Many people also expressed frustration that others could not see or understand the impact fatigue had on their daily lives.

Pain and physical symptoms

Joint pain is among the most common symptoms experienced by people living with lupus. For some people, pain is one of the first signs that something is wrong. For others, it becomes an ongoing challenge that affects the ability to do everyday things and quality of life.

Pain in lupus is often caused by inflammation, which is the body's natural response to injury or infection. In lupus, inflammation occurs even when there is no infection and, over time, it can damage healthy tissues and organs. Inflammation can affect the joints, muscles, tendons, and surrounding tissues. Unlike soreness that may occur after physical activity, inflammatory pain is often associated with stiffness, swelling, warmth, or reduced mobility.

Pain may affect many parts of the body, including:

- Hands and wrists
- Knees and ankles
- Feet and toes

- Shoulders
- Muscles throughout the body
- Tendons and connective tissues
- Living with chronic pain can be physically and emotionally exhausting. Pain may interfere with sleep, contribute to fatigue, reduce physical activity, and affect mood. Over time, these effects can reinforce one another and create a cycle that becomes increasingly difficult to break.

Managing pain often requires a combination of approaches, including medications, physical activity, stretching, pacing, stress management, and healthy sleep habits.

If pain is worsening, interfering with daily activities, or limiting your ability to stay active and independent, discuss it with your healthcare team. New or worsening pain may indicate increased disease activity or another health issue that requires attention.

Sleep challenges

Sleep problems are common among people living with lupus. Yet sleep is often overlooked when discussing disease management. Many factors can interfere with healthy sleep. Pain, anxiety, stress, disease activity, medication side effects, and concerns about the future can all make it difficult to get restorative rest.

People living with lupus may experience:

- Difficulty falling asleep
- Frequent waking during the night
- Unrefreshing sleep
- Insomnia
- Daytime sleepiness
- Difficulty maintaining a regular sleep schedule

Poor sleep can worsen many lupus symptoms. It can increase fatigue, affect concentration and memory, lower mood, and make pain more difficult to manage.

Although sleep problems are common, they should not be ignored. Improving sleep habits may help reduce the overall burden of lupus and improve quality of life.

Helpful strategies may include maintaining a regular sleep schedule, limiting screen time before bed, reducing caffeine intake later in the day, and discussing ongoing sleep concerns with your healthcare team.

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Mental health and lupus

Living with lupus involves much more than managing physical symptoms. The emotional impact of living with an unpredictable chronic disease can be substantial and deserves the same attention as other aspects of care.

Canadian researchers have shown that stress, anxiety and depression occur more frequently among people living with lupus than in the general population. These reactions are understandable. Lupus can affect health, relationships, employment, finances, family responsibilities, and future plans.

Mental health challenges associated with lupus may include:

- Insomnia
- Feelings of isolation
- Fear of disease progression
- Worry about future flares

Mental and physical health are closely connected. Anxiety, depression, and chronic stress can affect sleep, fatigue, physical activity, and your ability to follow your treatment plan. Likewise, ongoing pain, fatigue, and disease uncertainty can affect emotional health.

Seeking support is an important part of lupus self-management and should be viewed as a normal component of comprehensive care.

What people with lupus told us

ACE's National Survey on Lupus in Canada found that four in five people (80%) reported experiencing anxiety, depression, or insomnia related to their lupus.

Despite this high level of need, nearly two-thirds of people had not accessed mental health support during the previous year.

Participants identified barriers such as:

- Limited access to services
- Long wait times
- Cost
- Geographic barriers
- Difficulty finding appropriate support

These findings highlight an important reality. Mental health challenges are common among people living with lupus, yet many continue to face barriers to receiving care.

Support may come from health care professionals, peer support groups, family members, patient organizations, and others who understand the challenges of living with lupus.

Stress and lupus

Many people living with lupus notice that periods of increased stress are associated with worsening symptoms. While stress does not cause lupus, it may affect how people experience the disease.

Stress can influence sleep, energy levels, concentration, mood, and overall wellbeing. During particularly stressful periods, some people report increased fatigue, worsening pain, or greater difficulty coping with symptoms.

Although it is impossible to eliminate all sources of stress, learning healthy coping strategies can help improve resilience and quality of life.

Helpful stress-management approaches may include:

- Regular physical activity
- Mindfulness or meditation
- Deep breathing exercises
- Spending time outdoors
- Connecting with supportive friends and family
- Counselling or mental health support
- Participating in enjoyable activities

Different strategies work for different people. The goal is to identify approaches that fit your lifestyle and help you maintain balance during challenging periods.

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Did You Know?

Canadian researchers have found that **anxiety** and **depression** are highly prevalent among people living with lupus and are associated with poorer quality of life and disease outcomes.

Justin David Smith, Bo Pan, and Stephanie Keeling. Identifying the State of Mental Health Care in Canadian Adults with Systemic Lupus Erythematosus. The Journal of Rheumatology July 2025, jrheum.2025-0089

Mental health matters in Lupus care

- Mental health impacts overall wellbeing
- Support is important
- Screening and treatment can make a difference
- You are not alone

Understanding brain fog

Many people living with lupus report experiencing brain fog. Brain fog is not a medical diagnosis. It is a term people use to describe problems with thinking, memory, and concentration that can affect daily life. Some people notice occasional lapses in concentration, while others find it more difficult to remember information, stay organized, or complete tasks that require sustained focus.

Brain fog can show up in different ways, including:

- Difficulty concentrating
- Forgetting appointments or conversations
- Trouble finding the right words
- Difficulty multitasking
- Slower thinking or problem-solving
- Mental fatigue after routine activities

Brain fog may be influenced by several factors, including fatigue, poor sleep, pain, anxiety, depression, stress, medications, and active disease.

Many people find it helpful to use calendars, reminder systems, written notes, smartphone apps, and task lists to stay organized. Breaking larger activities into smaller steps and scheduling important tasks during periods of higher energy may also help.

If difficulties with thinking, memory, or concentration are worsening or interfering with work, school, relationships, or daily responsibilities, it is important to discuss them with your healthcare team.

Remember that experiencing brain fog does not mean you are losing your intelligence or abilities. For many people, thinking or memory difficulties fluctuate over time and improve when contributing factors are addressed.

Physical activity and lupus

ACE's National Survey on Lupus in Canada found that:

46% of people reported that lupus affects their ability to participate in physical activity.
Another 36% reported that lupus sometimes affects their ability to participate in physical activity.

When fatigue, pain, or stiffness are severe, physical activity may feel like the last thing you want to do. Some people worry that exercise will worsen symptoms, trigger a flare, or cause additional pain. These concerns are understandable. But research consistently shows that appropriate physical activity can be an important part of living well with lupus.

Physical activity does not cure lupus, but it can help improve strength, flexibility, endurance, sleep quality, mood, and overall health. Regular movement may also help reduce stiffness and support heart and bone health.

Activities that many people with lupus enjoy include:

- Walking
- Swimming or water-based exercise
- Cycling
- Stretching
- Yoga or tai chi
- Strength training

The goal is not to exercise intensely every day. The goal is to find safe and sustainable ways to keep your body moving. Even small amounts of regular movement can provide benefits, and it is important to start at a level that feels manageable for you.

Remember that some days will be better than others. During flares or periods of increased symptoms, you may need to adjust your activity level. Learning how to balance activity with recovery is one of the most important self-management skills you can develop.

Pacing and energy management

Many people living with lupus describe a frustrating cycle. On days when they feel well, they try to catch up on work, household tasks, errands, and social commitments. They push through fatigue to accomplish as much as possible. The following day, they may feel completely exhausted and need significant time to recover.

This pattern is sometimes called the “boom and bust” cycle.

Pacing is a strategy that helps you use your energy more consistently. Instead of using all of your energy at once, pacing encourages you to spread activities that matter most to you throughout the day and week in a way that is more sustainable.

Helpful pacing strategies include:

- Breaking large tasks into smaller steps
- Taking short breaks before becoming exhausted
- Prioritizing the most important activities
- Delegating tasks when possible
- Planning demanding activities on different days
- Learning to recognize your body’s early warning signs

Pacing does not mean giving up activities you enjoy. It means using your energy wisely so that you can continue participating in the activities that matter most to you.

Sun sensitivity and skin health

Many people living with lupus are sensitive to sunlight and ultraviolet (UV) light. Exposure to UV light can trigger skin symptoms and, in some people, may contribute to increased disease activity.

Sun sensitivity can be frustrating because sunlight is part of everyday life. Even routine activities such as walking, gardening, driving, or attending outdoor events may require additional planning.

Strategies that may help reduce UV exposure include:

- Using broad-spectrum sunscreen
- Wearing wide-brimmed hats
- Wearing long sleeves and protective clothing
- Seeking shade when possible
- Avoiding prolonged sun exposure during peak hours
- Discussing UV protection with your healthcare team

Protecting your skin does not mean avoiding outdoor activities altogether. Rather, it means taking reasonable precautions so you can participate more safely and comfortably.

If you notice new or worsening skin symptoms, discuss them with your healthcare team.

Nutrition and lupus

Many people living with lupus wonder whether there is a special diet that can reduce symptoms or prevent flares. Currently, there is no single diet proven to cure lupus or prevent disease flares.

Unfortunately, there is a great deal of conflicting information online, which can make it difficult to know what advice to follow. Healthy eating can support overall health and may help reduce some of the health risks associated with lupus. General healthy eating recommendations include:

- Eating a variety of fruits and vegetables
- Choosing whole grains
- Including lean sources of protein
- Choosing healthy fats such as fish, nuts, seeds, and olive oil
- Limiting highly processed foods
- Limiting excess sodium, saturated fat, and added sugars
- Maintaining a healthy weight

Heart and bone health are particularly important for people living with lupus. In addition, some people may develop low vitamin D levels because they spend less time in the sun to reduce flare risk.

It is also important to remember that supplements can interact with medications. Always discuss supplements with your healthcare team before starting them.

Rather than focusing on restrictive diets, most experts recommend a balanced and sustainable approach to healthy eating.

Support systems matter

Living with lupus can sometimes feel isolating because symptoms are often invisible. Family members, friends, and coworkers may not understand what it is like to live with an unpredictable disease or why you cancel plans, need additional rest, or appear well one day and unwell the next.

Educating the people closest to you about lupus can help them better understand your experiences and provide meaningful support. Having people who listen, understand, and provide practical assistance can help reduce stress and improve quality of life. Many people also find comfort in connecting with others who are also living with lupus. Sharing experiences, learning practical strategies, and realizing you are not alone can be incredibly valuable.

Support may come from many different sources, including:

- Family members
- Friends
- Healthcare professionals
- Peer support groups
- Patient organizations
- Counsellors or mental health professionals
- Community organizations

Remember

You may not be able to control every lupus symptom, but there are many things you can do to reduce their impact on daily life. Paying attention to fatigue, sleep, stress, physical activity, and mental health can help you feel more in control and better prepared to manage challenges when they arise. Small, consistent self-management habits often make a bigger difference than occasional large efforts.

Building your personal lupus toolkit

Living well with lupus often involves developing a collection of strategies, habits, resources, and supports that help you manage daily life.

Your personal lupus toolkit will be unique to you. What works well for one person may not work for another.

Your toolkit might include:

- A symptom journal
- Medication reminders
- A pacing plan
- Physical activity routines
- Stress-management techniques
- Healthy sleep habits
- Reliable educational resources
- Supportive family members or friends
- Contact information for your healthcare team

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Over time, you will learn which tools help you feel your best and which strategies are most useful during challenging periods. Be patient with yourself and remember that living well with lupus is a journey, not a destination.

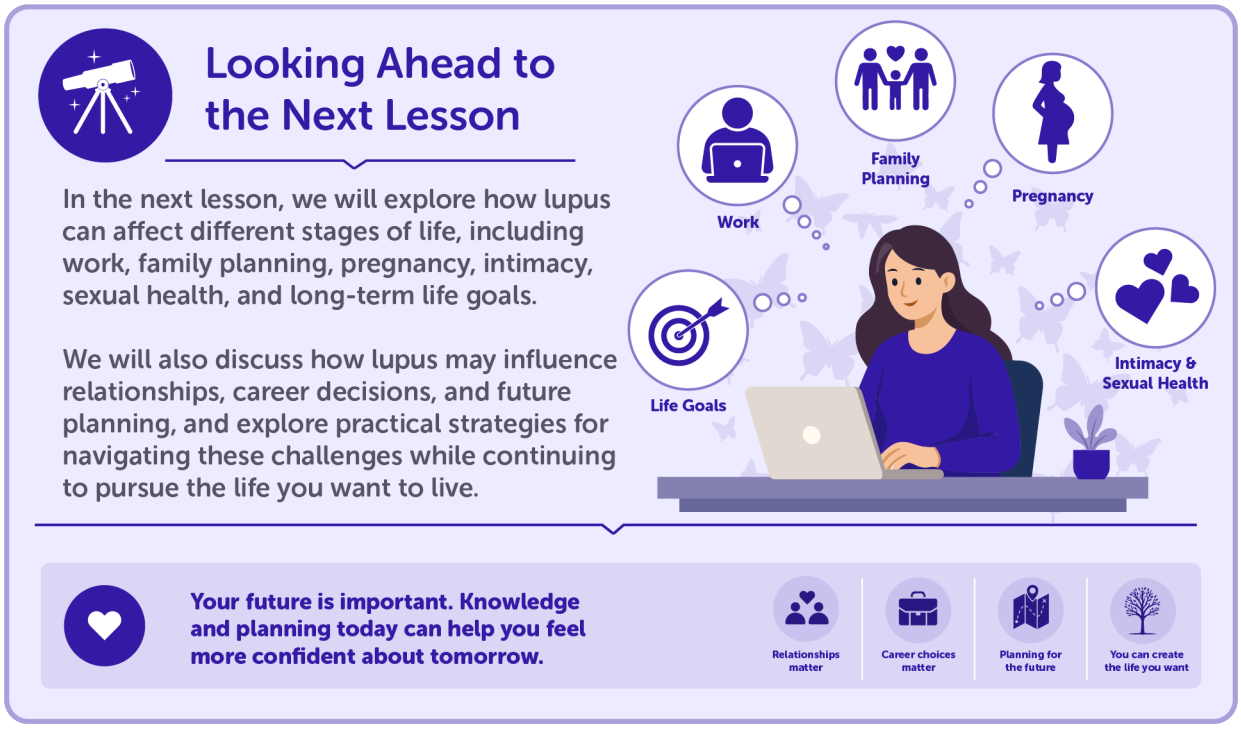
Questions to ask your doctor or specialist

Consider discussing the following questions with your healthcare team:

- Is my fatigue related to lupus activity, poor sleep, medications, or something else?
- What types of physical activity would be appropriate for me?
- Are there strategies that may help improve my sleep?
- How can I better manage stress and protect my mental health?
- Could my difficulties with memory, concentration, or brain fog be related to lupus?
- Are there any dietary changes or supplements I should consider?
- What resources are available if I need additional support?
- Remember that you are an important member of your healthcare team. The more effectively you communicate changes in your health, the better equipped your doctor or specialist will be able to support you.

Important Learning Points from Lesson 4

1. **Fatigue** is one of the most common and challenging symptoms of lupus and often affects quality of life more than people realize.
2. **Mental health**, including anxiety, depression, and stress, is an important part of lupus care and deserves attention and support.
3. **Regular physical activity**, pacing, and good sleep habits can help many people manage symptoms and to keep doing everyday activities.
4. **Protecting your skin** from ultraviolet (UV) light and recognizing personal triggers can help reduce disease activity and prevent flares.
5. **Living well with lupus** often requires a combination of medical care, self-management strategies, and support from family, friends, health care professionals, and community organizations.



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