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Lesson 5 – Lupus across life stages, reproductive health, intimacy, and work

In previous lessons, we explored what lupus is, how it is diagnosed and monitored, treatment approaches, and practical strategies for living well with the disease.

Lupus can also affect many important aspects of life beyond physical health. Decisions about work, relationships, family planning, pregnancy, caregiving responsibilities, and future goals may all be influenced by living with lupus.

Many people living with lupus successfully build careers, maintain meaningful relationships, raise families, and pursue their personal goals. But doing so often requires planning, communication, and support.

In this lesson, we explore how lupus can affect different stages of life and discuss practical strategies for navigating reproductive health, sexual health, relationships, employment, and caregiving responsibilities.

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

Lupus affects more than the immune system. It can influence major life decisions involving work, relationships, family planning, pregnancy, caregiving, and future goals.

Many people living with lupus worry about whether they can have children, maintain intimate relationships, continue working, care for loved ones, or achieve personal goals. These concerns are common and understandable.

Research has shown that conversations about sexual or reproductive health do not always occur routinely during lupus care. Many patients report wanting earlier and more proactive discussions about topics such as pregnancy, family planning, contraception, fertility, and medication safety. Studies involving both patients and doctors/specialists have identified barriers to initiating conversations about sexual or reproductive health during routine clinic visits. And, if they do occur, patients and doctors describe that these conversations can feel difficult or awkward to raise during busy medical appointments. As a result, important questions may go unasked and opportunities for planning may be missed.

Understanding how lupus may affect different stages of life can help you prepare, ask informed questions, access appropriate support, and make informed decisions that reflect both your health needs and your future priorities.

With the right information, support, and planning, you can feel more confident about the future you want to build.

Employment and workplace accommodations

Many people living with lupus continue to work successfully throughout their lives. Work can provide more than financial security. It can also offer purpose, social connection, independence, and a sense of accomplishment.

At the same time, lupus symptoms such as fatigue, pain, brain fog, sensitivity to sunlight, and unpredictable flares can make it more difficult to meet workplace demands. Some people find that symptoms affect their productivity, concentration, stamina, or ability to maintain a regular work schedule.

Research has shown that maintaining employment can have important benefits for both physical and emotional health. However, many people living with lupus face difficult decisions about whether to disclose their diagnosis to an employer, request accommodations, or modify their work responsibilities. Some worry about stigma, misunderstandings, or the potential impact on career opportunities.

The good news is that workplace accommodations can often help people remain productive and continue participating in the workforce. Accommodations are adjustments that help employees perform their jobs safely and effectively while managing health challenges.

Examples of workplace accommodations may include:

- Flexible scheduling or modified work hours
- Hybrid or remote work arrangements
- Additional rest breaks during the day
- Time off for medical appointments
- Ergonomic workstations or supportive equipment
- Reduced physical demands
- Adjustments to lighting or environmental conditions
- Modified duties during periods of increased symptoms
- Temporary part-time schedules or gradual return-to-work plans

Not every person with lupus will need accommodations, and not everyone will choose to disclose their diagnosis to an employer. Decisions about disclosure are highly personal and may depend on workplace culture, job responsibilities, symptom severity, and individual circumstances.

Deciding whether to tell your employer

One of the most difficult workplace decisions for many people living with lupus is whether to tell an employer about their condition.

There is no single right answer. Some people choose to share information about their lupus because they need workplace accommodations or support. Others prefer to keep their health information private, particularly if their symptoms are well controlled and do not affect their ability to do their job.

The decision to disclose may depend on several factors, including:

- Whether symptoms are affecting work performance
- The need for workplace accommodations
- Workplace culture and relationships with supervisors

- Job security and employment status
- Personal comfort discussing about health information

Some people worry that disclosing a chronic disease could lead to misunderstandings, stigma, or concerns about career advancement. Others find that sharing information helps employers better understand their needs and allows accommodations to be put in place.

Remember that you are not required to share every detail about your disease. If accommodations are needed, discussions can often focus on what support or adjustments would help you perform your job successfully rather than on the specifics of your diagnosis.

If you are unsure whether to disclose your lupus, consider discussing the decision with your healthcare team, human resources department, union representative, or another trusted advisor.

What People with Lupus Told Us

ACE's National Survey on Lupus in Canada findings found that lupus can significantly affect **employment**.

Many people described challenges maintaining work responsibilities because of fatigue, pain, problems with thinking, memory, and concentration, and fluctuating disease activity:

Approximately **one in five** reported being unable to work because of lupus

Approximately **one in five** reported reducing thier work hours

Research has shown that many people living with lupus benefit from workplace accommodations.

Research has shown that many people living with lupus benefit from workplace accommodations. Flexible schedules, opportunities to work from home, modified duties, and other adjustments may help people remain employed and continue participating in meaningful work.

If lupus symptoms are affecting your ability to work, consider speaking with your healthcare team about strategies and accommodations that may help you continue working successfully.

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Reproductive health and family planning

For many people living with lupus, decisions about pregnancy and family planning can feel complicated. Disease activity, medications, fertility concerns, and potential pregnancy risks may all influence decision-making.

Fortunately, many people with lupus can have healthy pregnancies and families. The key is planning ahead and having open conversations with your healthcare team.

Important topics to discuss include:

- Pregnancy goals and timing
- Disease activity and disease control
- Medication safety before and during pregnancy
- Fertility concerns
- Contraception options
- Risks related to lupus and pregnancy
- Monitoring requirements during pregnancy

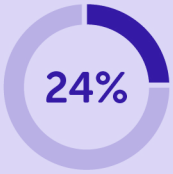
These discussions are most effective when they happen before pregnancy is being actively considered.

What People with Lupus Told Us

ACE's National Survey on Lupus in Canada identified an important **gap in reproductive health discussions**.

Having open, proactive conversation about reproductive health can help people with lupus plan for the future with confidence.

- Start the conversation
- Get the support you need
- Plan with confidence



Nearly one in four people (**24%**) reported that they had not received guidance about pregnancy or family planning from their health care providers, despite being interested in receiving this information.

This highlights an important gap. Many people want information and support to help them make informed decisions about their reproductive health, but those conversations are not always happening.

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Pregnancy and lupus

Many people living with lupus can have successful pregnancies. However, lupus pregnancies often require additional planning and monitoring. The safest pregnancies generally occur when lupus has been stable and well controlled for at least six months before conception.

Pregnancy is often described as a partnership between the patient and healthcare team. Planning ahead helps reduce risks and supports healthier outcomes for both parent and baby.

Doctors or specialists may recommend:

- Reviewing medications before pregnancy
- Discussing breastfeeding and medication safety
- Assessing disease activity
- Evaluating kidney involvement and other organ involvement
- Reviewing blood tests
- Coordinating care between specialists
- Developing a monitoring plan

Contraception and medication conversations

Contraception is an important component of reproductive health planning for many people with lupus. Some medications used to treat lupus may not be appropriate during pregnancy. In addition, some forms of contraception may be more suitable than others depending on disease activity, blood clotting risk, and other health factors.

The best contraceptive choice varies from person to person.

Questions to discuss with your healthcare team include:

- Which contraceptive methods are safest for me?
- Could my medications affect pregnancy?
- Are there medications that should be changed before pregnancy?
- How far in advance should pregnancy planning begin?

These conversations help ensure that reproductive decisions align with both health needs and personal goals.

Hormonal changes

Perimenopause, the transitional period leading up to menopause when hormone levels begin to change, and menopause itself can cause symptoms that sometimes overlap with those of lupus symptoms, including:

- Fatigue
- Sleep disturbances
- Mood changes
- Joint pain
- Difficulty concentrating
- Changes in sexual wellbeing

Because many of these symptoms can occur in both lupus and hormonal transitions, it can sometimes be difficult to determine what is causing a change in how you feel. If symptoms are affecting quality of life, it is important to discuss them with your healthcare team so that appropriate evaluation and management strategies can be considered.

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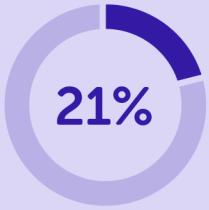
Sexual health and intimacy

Sexual health and intimacy are important parts of overall wellbeing, yet they are rarely discussed during healthcare visits. Lupus can affect intimacy in many ways. Fatigue, pain, stiffness, medication side effects, emotional stress, anxiety, depression, and body image concerns may all influence sexual wellbeing.

These challenges are common and should not be viewed as something people must simply accept or manage alone. Open communication with doctors or specialists can help identify strategies that improve comfort, confidence, and intimacy.

What People with Lupus Told Us

ACE's National Survey on Lupus in Canada found that sexual health was affected for most respondents.



Only **21%** reported that lupus had no impact on their sexual wellbeing.

People reported:

- Fatigue affecting intimacy ---------- 49%
- Decreased libido ---------- 41%
- Changes in confidence or body image ---------- 39%
- Physical symptoms affecting intimacy ---------- 30%
- Anxiety or depression affecting sexual wellbeing -------- 23%

These findings demonstrate that sexual health is a significant quality-of-life issue for many people living with lupus.

- Talk openly
- Bring it up wit your healthcare team
- Seek support
- You are not alone
- Support is available

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Body confidence and self-image

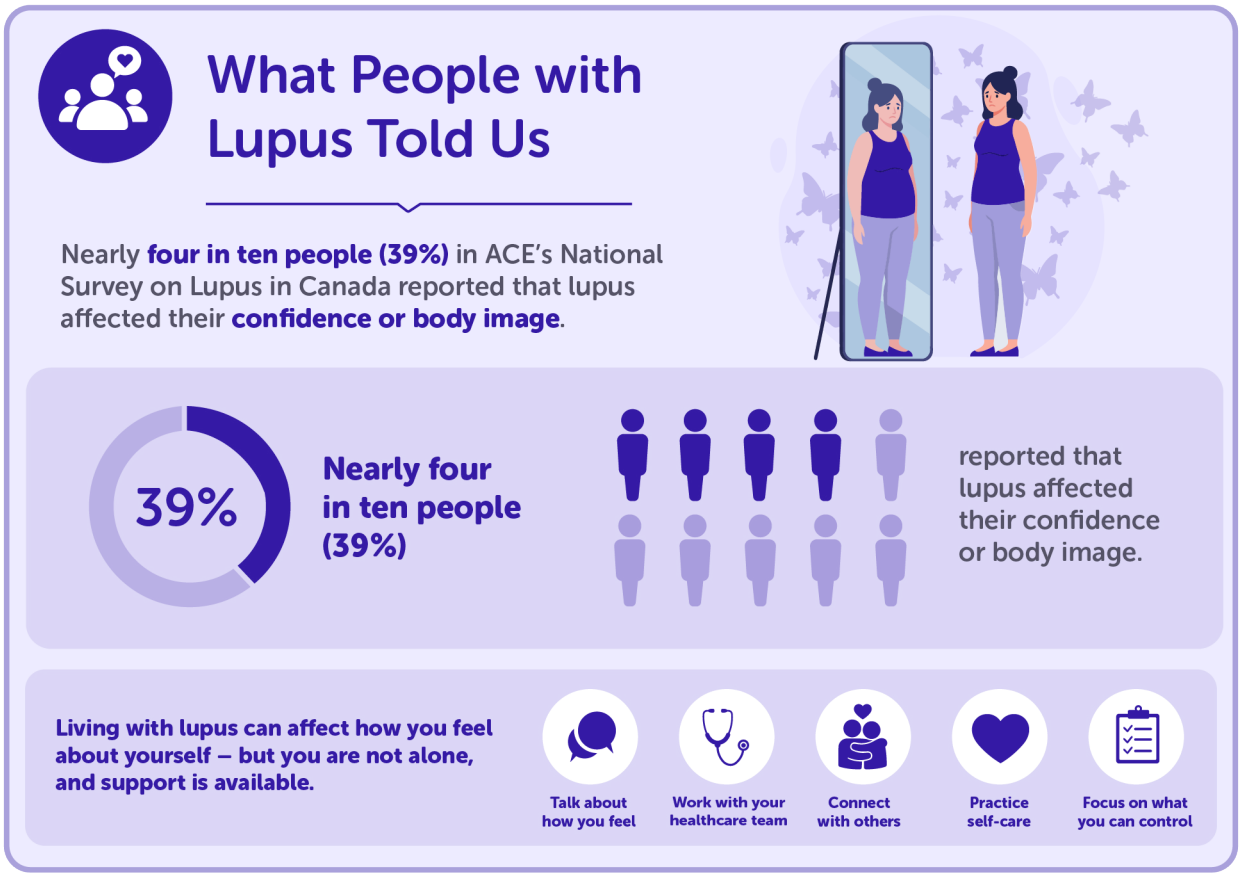
Living with lupus can sometimes affect how people feel about themselves.

Visible signs of disease, medication side effects, hair loss, weight changes, rashes, fatigue, and physical limitations may affect confidence and self-esteem. Some people report feeling self-conscious about changes in appearance. Others worry about how lupus affects relationships, dating, intimacy, or social participation.

It is important to remember that these feelings are common and understandable.

Building confidence often involves:

- Focusing on overall wellbeing rather than appearance alone
- Connecting with supportive people
- Seeking counselling or mental health support when needed
- Learning more about lupus and its effects
- Practicing self-compassion



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Relationships and caregiving

Lupus affects not only individuals but also the people around them. Partners, family members, friends, children, and caregivers may all be affected by the challenges of living with a chronic illness.

People living with lupus may sometimes feel guilty about:

- Cancelling plans
- Needing help
- Asking others to share responsibilities
- Having unpredictable symptoms

Open communication can help others better understand what you are experiencing. Many people find that educating loved ones about lupus improves understanding and strengthens support systems.

Questions to ask your healthcare team

Consider discussing the following questions with your healthcare team:

- Is my lupus well controlled enough to consider pregnancy?
- Are my medications safe if I am planning a pregnancy?
- Which contraception options are appropriate for me?
- Could menopause be affecting my symptoms?
- Are my symptoms affecting sexual health or intimacy?
- What resources are available to help with body image or emotional wellbeing?
- What workplace accommodations might help me manage lupus at work?
- Are there supports available if caregiving responsibilities are becoming difficult to manage?
- What specialists should be involved in my reproductive health care?
- Should I consider discussing my lupus with my employer, and what workplace accommodations might be helpful for me?
- What information might I need if I decide to request workplace accommodations?

Remember that reproductive health, sexual health, employment concerns, and quality-of-life issues are important aspects of lupus care and deserve discussion.

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Important Learning Points from Lesson 5

1. **Reproductive health, family planning, and pregnancy** are important parts of lupus care and should be discussed proactively with your healthcare team.

2. Many people living with lupus experience challenges **related to intimacy, sexual health, body confidence, and relationships.**

3. Lupus can affect **employment, productivity, and caregiving responsibilities,** but workplace accommodations and support strategies may help.

4. **Hormonal changes** can affect symptoms and quality of life and may require additional discussion with your healthcare team.

5. **Open communication, planning, and support** can help people with lupus make informed decisions throughout different stages of life.

Looking Ahead to the Next Lesson

In the final lesson, we will focus on becoming an **informed and active partner** in your lupus care.

We will discuss **preparing** for healthcare appointments, **communicating** effectively with doctors or specialists, shared decision-making, finding reliable information, participating in research, and connecting with **patient organizations** and **support networks**.

We will also explore how people living with lupus can help shape the future of lupus care through **advocacy**, **education**, and **community engagement**.

Get ready to take an active role in your care and in the lupus community.

- Prepare for appointments
- Communicate effectively
- Make decisions together
- Find reliable information
- Participate in research
- Connect with organizations and support networks
- Advocate, educate, and create change

References

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