JHEd Lupus

Lesson 6 – Equity, access, and advocating for better lupus care

Throughout this course, we have explored many aspects of living with lupus, including understanding the disease, diagnosis and monitoring, treatment approaches, symptom management, mental health, sexual and reproductive health, relationships, employment, and daily life challenges.

While advances in lupus care have improved outcomes for many people, access to care is not the same for everyone. Factors such as where a person lives, access to specialists, medication coverage, financial resources, cultural background, and availability of support services can all influence healthcare experiences and outcomes.

In this final lesson, we will explore some of the barriers people living with lupus may face and discuss practical strategies for navigating the healthcare system, accessing support, finding trustworthy information, and advocating for better lupus care.

Why This Matters

Even the most effective treatments cannot help if people are unable to access them.

Many Canadians living with lupus **face challenges finding specialists, obtaining medications, travelling long distances for care, accessing support services,** or **finding information** that meets their needs. These barriers can affect **disease management, quality of life, employment, mental health,** and **overall wellbeing**.

Understanding these challenges can help people living with lupus **navigate the healthcare system** more effectively, **access available resources**, and **advocate for the care and support** they need.

- Finding specialists
- Obtaining medications
- Travelling long distance for care
- Accessing support services
- Finding information that meets their needs
- Impact on quality of life, employment, mental health, and wellbeing

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.

Access to care and specialist shortages

Lupus is a complex disease that can affect many parts of the body, including the joints, skin, kidneys, lungs, heart, and nervous system. Because symptoms can change over time and disease activity can fluctuate, many people living with lupus require ongoing care from a rheumatologist and, in some cases, other specialists.

Unfortunately, accessing that care is not always easy.

Across Canada, many communities face shortages of health care professionals, including rheumatologists. In some regions, patients may wait months to see a specialist or travel considerable distances to receive care. Delays can be particularly challenging for individuals experiencing worsening symptoms, medication side effects, or concerns about disease activity.

Access challenges can also affect diagnosis. Many people with lupus experience symptoms for months or years before receiving a diagnosis. Because lupus symptoms can mimic those of other diseases, some patients report feeling dismissed, misunderstood, or told their symptoms are caused by stress, aging, or unrelated health issues.

ACE's National Survey on Lupus in Canada found that many people continued to face barriers to care after diagnosis. One-third reported long wait times for care, while others identified distance to health care providers, costs, and lack of specialist access as significant challenges. These findings highlight that managing lupus often involves navigating a healthcare system that can be difficult to access and coordinate.

Rural and remote care

Where a person lives can have a significant impact on their healthcare experience.

People living in rural and remote communities often face challenges that go beyond simply finding a specialist. Accessing care may involve travelling several hours for

appointments, arranging transportation, taking time away from work, finding childcare, paying for parking or accommodation, and navigating weather-related disruptions.

For individuals living with lupus, these challenges can be particularly burdensome because ongoing disease management often requires regular medical appointments, bloodwork, monitoring tests, and access to other healthcare services such as physiotherapy, occupational therapy, mental health support, and rehabilitation programs.

What might be a routine medical appointment for someone living in a large urban centre can become a full-day commitment for someone living in a rural area.

Travel requirements can also affect continuity of care. Some patients may delay appointments, postpone recommended tests, or choose not to seek care for new symptoms because of the practical challenges involved. Over time, these barriers can affect disease management and overall health outcomes.

In ACE's National Survey on Lupus in Canada, a person described the reality of attending specialist appointments from a rural community:

"My rheumatologist is 45 minutes away. I drive from a rural town into Brampton. I don't drive in the city. The parking lot is paid. The pay machine is very slow and not sheltered from the sun. The elevators are usually out, and I have to climb 3 flights of stairs. My appointments are no more than 10 minutes long."

Equity and lupus care

Not everyone experiences lupus in the same way.

Research shows that lupus is more common among some populations, including Indigenous Peoples, Black communities, and some other racialized groups. Studies have also found that lupus may be more severe and associated with poorer outcomes in some of these populations.

At the same time, healthcare experiences are influenced by factors that extend beyond biology. Access to healthcare services, transportation, income, education, health literacy, language, social support, and cultural factors can all affect a person's ability to obtain timely and appropriate care.

These influences are sometimes referred to as the social determinants of health because they affect opportunities to achieve and maintain good health.

When barriers related to healthcare access are combined with higher disease burden, health inequities can become more pronounced. Understanding these differences is important because equitable care means ensuring that everyone has access to the services, support, and treatment they need to achieve the best possible outcomes.

Recognizing inequities is not about treating people differently. Rather, it is about understanding that people may face different challenges and ensuring that healthcare systems respond appropriately to those needs.

Culturally safe care

People living with lupus come from diverse cultural, linguistic, and community backgrounds. Healthcare is most effective when people feel respected, understood, and supported.

Culturally safe care means healthcare that recognizes and respects an individual's values, beliefs, traditions, lived experiences, and identity. It involves building trust, listening carefully, and acknowledging that healthcare experiences may be shaped by culture, history, language, and personal circumstances.

For Indigenous Peoples, culturally safe care may also involve recognizing the ongoing impacts of colonization, systemic racism, and historical experiences that have affected trust in healthcare systems. As one person reports in ACE's National Survey on Lupus in Canada: "I am very discouraged there is no support Lupus sharing circle on my home First Nations territory. I would love to talk with others who have been stricken with Lupus. The Lupus journey for me is a lonely one."

Across Canada, arthritis organizations and Indigenous partners have worked together to promote greater understanding of culturally safe care through initiatives such as the Arthritis Community Learning Circle. These efforts encourage health care providers and organizations to learn from Indigenous perspectives and improve care experiences for Indigenous patients and communities.

Information, education, and support

Living with lupus often means learning how to manage a disease that can be unpredictable and affect many aspects of daily life.

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People living with lupus frequently seek information about symptoms, treatments, medications, fatigue, physical activity, mental health, pregnancy, employment, and strategies for managing flares. As new research emerges, many people also want help understanding how new discoveries and treatment options may apply to their own health.

Access to trustworthy information can help people feel more confident, participate in healthcare decisions, and better understand the choices available to them. Education can also reduce uncertainty and provide practical tools for managing daily challenges.

Support is equally important. Many people living with lupus benefit from connecting with others who understand the realities of living with a chronic disease. Whether through support groups, patient organizations, educational programs, or online communities, support can reduce feelings of isolation and provide encouragement during difficult periods.

Did You Know?

Many people living with lupus want **more than medical treatment alone**.

ACE's National Survey on Lupus in Canada found that people identified information about **research advances, self-management education, mental health support,** and **opportunities to connect with others living with lupus** as important unmet needs. These findings demonstrate that education and support are important components of comprehensive lupus care.

People living with lupus said these are important unmet needs

Information about research advances
Staying informed about new treatments and research opportunities.

Self-management education
Practical tools and education to manage lupus day to day.

Mental health support
Access to emotional wellbeing and mental health resources.

Opportunities to connect with others living with lupus
Building community and sharing experiences.

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Self-advocacy

Self-advocacy is an important skill for people living with chronic diseases.

At its core, self-advocacy means communicating your needs, asking questions, and actively participating in decisions about your healthcare. It does not mean becoming a medical expert or managing lupus on your own. Rather, it means working in partnership with your healthcare team and ensuring that your concerns, priorities, and goals are part of the conversation.

For many people, self-advocacy can feel uncomfortable at first. Some worry about asking too many questions or taking up too much time during appointments. Others may feel uncertain about how to raise concerns when they disagree with a recommendation or feel their symptoms are not being fully understood.

However, self-advocacy can play an important role in improving healthcare experiences. People who prepare for appointments, track symptoms, ask questions, and seek clarification often feel more informed and better equipped to participate in decisions about their care.

Self-advocacy may include:

- Preparing questions before appointments
- Keeping track of symptoms and treatment responses
- Asking for clarification when information is unclear
- Requesting referrals when appropriate
- Seeking a second opinion when necessary
- Discussing barriers that affect your ability to follow treatment recommendations

Improving lupus care is not only the responsibility of individual patients and doctors or specialists. Across Canada, patient organizations, health care professionals, researchers, and community leaders are working together to improve access to care, reduce inequities, and strengthen support for people living with arthritis and related diseases through initiatives such as Arthritis Action Now, Canada's national action plan for arthritis. While change can take time, patient voices continue to play an important role in shaping the future of care.

Trusted sources of information and support

The internet provides access to enormous amounts of health information. Unfortunately, not all information is accurate, evidence-based, or trustworthy.

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When seeking information about lupus, it is important to rely on credible sources that are informed by research, clinical expertise, and patient experience.

Trusted sources may include health care professionals, patient organizations, educational programs, and reputable health agencies. These organizations can help patients better understand lupus, stay informed about new developments, and access resources that support disease management and wellbeing.

Reliable information helps people make informed decisions and reduces the risk of misinformation, confusion, and unnecessary anxiety.

Examples of trusted sources include:

- Your rheumatologist and healthcare team
- **Arthritis Consumer Experts (ACE)**
- **Arthritis Research Canada**
- **Lupus Canada**
- **Lupus Ontario**
- **Lupus Society of Alberta**
- **BC Lupus Society**
- **Lupus Foundation of America**
- Clinical practice guidelines from organizations such as the **Canadian Rheumatology Association**, **European Alliance of Associations for Rheumatology**, and the **American College of Rheumatology**

Research studies and clinical practice guidelines can provide valuable information about lupus, new treatments, and advances in care. Because research findings or clinical guidelines can sometimes be complex and are often written for academic audiences, it can be helpful to discuss questions about research with your healthcare team and consider how the information applies to your own health and treatment goals.

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Remember

Access to lupus care is not the same for everyone. Factors such as geography, income, race, culture, access to specialists, and availability of support services can influence health outcomes and quality of life.

While some barriers may be outside your control, staying informed, asking questions, seeking support, and advocating for your needs can help you navigate the healthcare system and access the care you deserve.

Every person living with lupus deserves timely, equitable, and compassionate care. By sharing experiences, participating in education, and supporting efforts to advocate for better care, people living with lupus help improve the future of lupus care for themselves and others.

Questions to ask your healthcare team

- Are there additional health care professionals who should be involved in my care?
- What resources are available if I live in a rural or remote community?
- Are there support programs that can help with medication costs?
- What reliable sources of information do you recommend?
- Are there local or online support groups available?
- What can I do if I feel my symptoms are not being adequately addressed?
- How can I become a stronger advocate for my healthcare needs?
- What educational programs or resources would help me better understand lupus?

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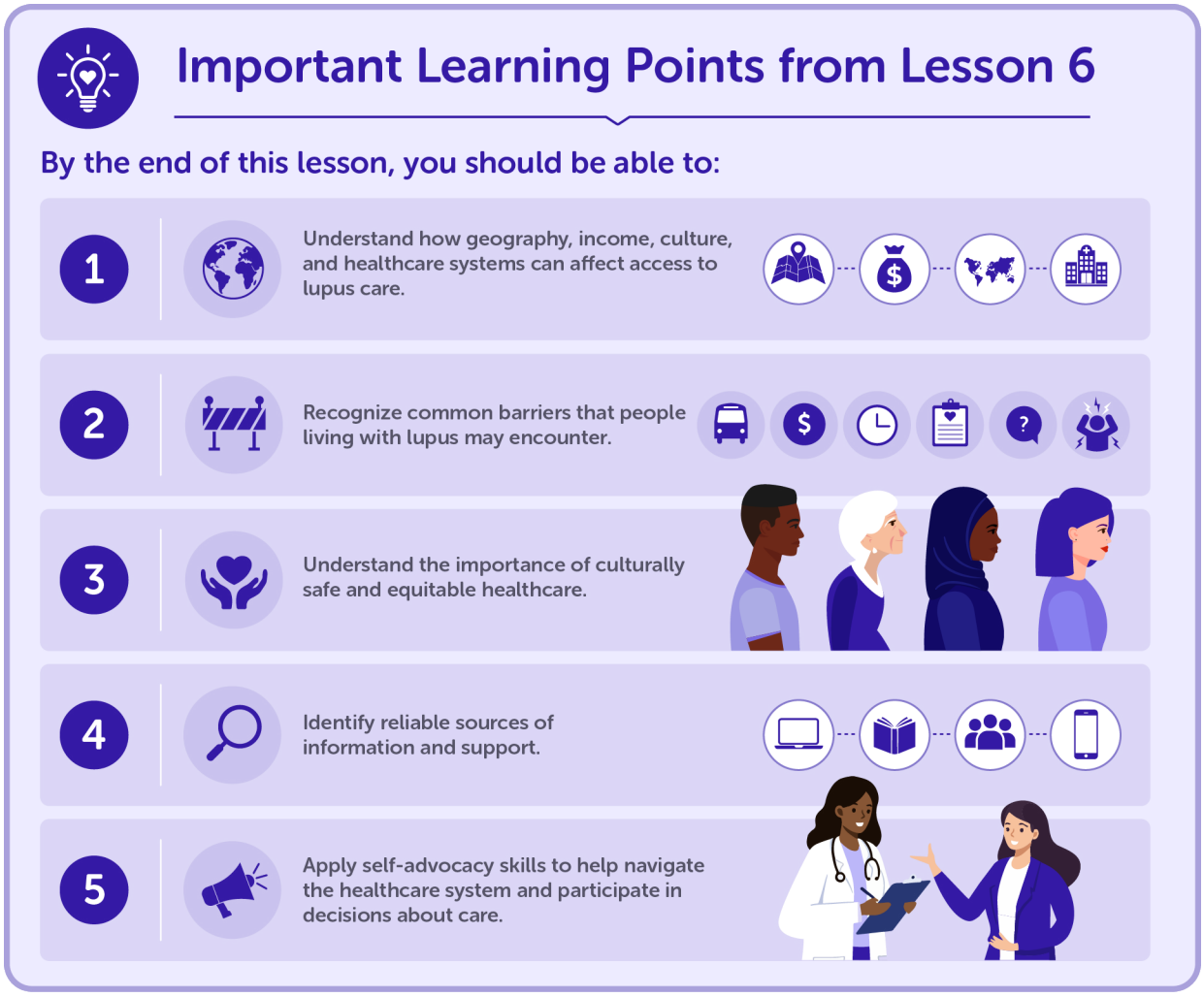

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