JHEd Lupus

Lesson 2 – Diagnosis, Monitoring, and Knowing When to Seek Care

In Lesson 1, we learned that lupus is a complex and unpredictable disease that can affect many parts of the body. Because symptoms can change over time, ongoing monitoring is an essential part of lupus care.

Many people living with lupus wonder whether a new symptom is related to their disease, whether they should contact their doctor or specialist, or whether a symptom represents a flare. Understanding how lupus is diagnosed and monitored can help you feel more confident in recognizing changes in your health and communicating them clearly.

This lesson explores the tests commonly used to diagnose and monitor lupus, symptoms that should be tracked, warning signs that require medical attention, and practical strategies for preparing for healthcare appointments.

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 symptoms can change over time, and some changes are easier to recognize than others. Understanding how lupus is diagnosed and monitored, what laboratory tests are used, and when to seek medical attention can help you recognize important changes early and play an active role in protecting your long-term health.

The more informed you are about monitoring your lupus, the better prepared you will be to communicate with your healthcare team and make informed decisions about your care.

Symptoms can change over time. Some changes are easier to recognize than others.

Understanding diagnosis and monitoring helps you know what tests are used and why they matter

Recognizing changes early can help you seek medical attention when it's needed

You play an active role in protecting your long-term health

Being informed empowers you to communicate effectively and make informed decisions about your care

Knowledge is power. Understanding how lupus is monitored helps you take control of your health.

How Is lupus diagnosed?

Many people living with lupus describe a long and sometimes frustrating diagnostic journey. Symptoms often develop gradually, and some people may not have enough signs, symptoms, or test results for their specialist to confidently diagnose lupus right away.

Several key factors contribute to delays in finding out what's wrong. First, lupus symptoms can be like those of many other diseases. Fatigue, headaches, joint pain, and rashes are common symptoms that can occur in numerous diseases. Second, symptoms may come on slowly and affect different organs at different times. This can make it difficult for doctors or specialists to identify a clear pattern early in the disease. Third, there is no single test that confirms lupus. Rather than relying on a single test, doctors or specialists look for patterns of symptoms and laboratory findings that are consistent with lupus.

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For some people, the emotional impact of delayed diagnosis can be significant. Feelings of uncertainty, frustration, anxiety, and isolation are common. Understanding that these experiences are shared by many others living with lupus can be reassuring.

Diagnosis typically involves a combination of:

- Medical history
- Physical examination
- Blood or urine tests
- Imaging tests when needed
- Assessment of symptoms over time

What People with Lupus Told Us

The diagnostic journey described by many people in ACE's National Survey on Lupus in Canada reflects the challenges to getting a diagnosis.

People frequently reported being misdiagnosed, having symptoms dismissed, or having trouble accessing specialists before receiving a diagnosis.

These experiences highlight the importance of persistence, advocacy, and access to specialists in getting the right diagnosis.

Misdiagnosis
Many people were told they had other conditions before lupus was considered

Symptoms dismissed
Many felt their symptoms were minimized or not taken seriously

Barriers to care
People reported difficulty accessing specialists and long wait times

Diagnosed by a rheumatologist
Nearly two-thirds were ultimately diagnosed by a rheumatologist

Years of uncertainty
Some described years of uncertainty before receiving answers and care

Understanding blood tests

Blood tests play an important role in both diagnosis and ongoing monitoring.

Test	Why the test is important
ANA	Helps determine whether lupus may be present. A positive ANA alone does not mean you have lupus.
Anti-dsDNA	Helps support a lupus diagnosis and may indicate increased disease activity, particularly if the kidneys are affected.
C3/C4	Low levels may indicate that lupus is more active.
CBC	Checks your red blood cells, white blood cells, and platelets, and helps monitor your health and medication safety.
ESR/CRP	Help measure inflammation in the body, although they are not specific to lupus.

Why urine testing is important

As discussed in Lesson 1, lupus nephritis occurs when lupus affects the kidneys. Kidney disease may develop without obvious symptoms. Even if you feel well, regular blood and urine tests remain one of the best ways to identify problems early and protect kidney health.

Urine tests may detect:

- Protein in the urine
- Blood in the urine
- Signs of kidney inflammation
- Your doctor or specialist may also order blood tests to see how well your kidneys are working and may monitor blood pressure because high blood pressure can be a sign of kidney involvement.

Even when you feel well, routine urine testing remains an important part of monitoring lupus.

Recognizing kidney warning signs

Early identification and treatment of lupus nephritis can significantly improve outcomes. Although kidney disease can develop without symptoms, some warning signs should prompt medical attention.

These may include:

- Swelling in the feet, ankles, or legs
- Puffiness around the eyes
- Foamy urine
- Blood in your urine
- Sudden weight gain from fluid retention
- Elevated blood pressure
- If you experience any of these symptoms, contact your doctor or specialist promptly.

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Knowing when to seek urgent care

Certain symptoms require prompt medical attention.

Contact your health care provider or seek urgent medical care if you experience:

- New chest pain
- Difficulty breathing
- Severe swelling
- Sudden changes in vision
- New seizures
- Severe headaches unlike your usual headaches
- Significant weakness or numbness
- Blood in the urine
- High fever

Although these symptoms do not always indicate a lupus-related emergency, they should be assessed promptly.

In ACE's National Survey on Lupus in Canada, people identified several barriers to receiving timely lupus care after diagnosis. One in three reported long wait times for care, while others cited distance to health care providers (**22%**), cost (**21%**), and lack of access to specialists (**20%**) as major challenges. These findings highlight the importance of preparing for appointments, tracking symptoms, and making the most of available clinical time.

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Barriers to Timely Care

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Top Barriers Reported

33% Long wait times for care *1 in 3 people*

22% Distance to health care providers

21% Cost

20% Lack of access to specialists

How You Can Take Action

Prepare for appointments
Write down your questions and concerns.

Track your symptoms
Keep a record to share with your healthcare team.

Make the most of your time
Focus on what matters most during your visit.

Tracking symptoms

Many people living with lupus find it helpful to track symptoms between appointments.

Keeping a symptom journal can help you identify patterns and provide useful information to your healthcare team. Some people use paper journals while others use smartphone apps or digital tools. The method matters less than the consistency. Even brief notes can help you recognize patterns over time.

The importance of symptom monitoring is reflected in findings from ACE's National Survey on Lupus in Canada. People reported that lupus frequently affected household work, social activities, physical activity, employment, and other aspects of daily life.

Because symptoms can change over time and affect multiple body systems, tracking changes in fatigue, pain, swelling, rashes, physical function, and overall wellbeing can help

identify patterns and support more informed discussions with health care providers. Tracking symptoms can also help you recognize improvements and better understand how treatments are working.

You may wish to track:

- Fatigue levels
- Pain levels
- Joint swelling
- Rashes
- Sleep quality
- Physical activity
- Medication changes
- Potential triggers
- New symptoms
- How symptoms affect daily activities

Remember

You do not need to track every symptom every day. Even brief notes about changes in fatigue, pain, swelling, rashes, medications, or new symptoms can help you identify patterns over time and support more productive conversations with your healthcare team.

Preparing for appointments

Appointments with your doctor or specialist are often brief. Preparing ahead of time can help ensure that your most important concerns are addressed. Being organized and actively participating in discussions can help ensure that important concerns are addressed and treatment decisions reflect your needs and priorities.

Consider bringing:

- A list of symptoms or concerns
- Questions about treatment
- Recent medication changes
- Results from symptom tracking
- Information about side effects
- Updates about work, school, family, or daily functioning
- A family member or friend if you would like support or help remembering information
- Many people find it helpful to prioritize their top two or three concerns before each appointment.

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Questions for your doctor or specialist:

- Are my symptoms consistent with a flare
- What laboratory tests are monitoring my disease activity? What do my recent tests tell us?
- How are my kidneys being monitored?
- What symptoms should prompt a call to the clinic?
- Is my treatment plan achieving its goals?
- Are there side effects I should be watching for?
- Are there other members of the healthcare team who could help me manage symptoms?

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 2

1. **There is no single test that diagnoses lupus.** Diagnosis is based on a combination of symptoms, physical examination, laboratory tests, and your specialist's assessment.
2. **Regular monitoring helps** identify disease activity, treatment response, medication safety concerns, and potential organ involvement before serious complications occur.
3. **Changes in symptoms**, especially those involving the kidneys, heart, lungs, or nervous system, should be reported promptly to your healthcare team.
4. **Tracking symptoms and preparing for appointments** can improve communication, support shared decision-making, and help you make the most of limited clinical time.

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Looking Ahead to the Next Lesson

Monitoring lupus is not simply about laboratory tests. It is about understanding your disease, recognizing meaningful changes, and working collaboratively with your healthcare team.

In the next lesson, we will explore treatment options, treatment goals, medication safety, and how shared decision-making can help people living with lupus make informed choices about their care.

Your knowledge, awareness, and patnership with your heathcare team are key to living well with lupus.

References

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