JHEd Lupus

Lesson 1 – Understanding lupus

For some, the journey to a lupus diagnosis can be long, confusing, and frightening. Symptoms may appear gradually, come and go without warning, or affect different parts of the body at different times. Because lupus can affect many organs and systems throughout the body, understanding the disease is often the first step toward feeling more confident and informed. In this lesson, we will explore what lupus is, how it affects the body, common symptoms, the connection between lupus and arthritis, the importance of recognizing flares, and why ongoing monitoring is essential.

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

Learning that you have lupus can raise many questions and uncertainties. Understanding what lupus is, why symptoms vary, and how the disease affects the body can help you feel more confident in discussing your care, recognizing important changes in your health, and making informed decisions with your healthcare team.

- Feel more confident discussing your care
- Better understand your symptoms and health
- Recognize important changes in your health
- Make informed decisions with your healthcare team
- Feel more empowered in your lupus journey

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What is lupus?

Lupus is a chronic autoimmune disease. Autoimmune means the immune system mistakenly attacks the body's own healthy tissues instead of protecting it from infection

Normally, the immune system protects the body from infections and other threats. In lupus, the immune system mistakenly attacks healthy tissues and organs, causing inflammation and damage.

Inflammation 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.

Because lupus can affect many parts of the body, it is often called a systemic disease. Systemic means the disease can affect many organs and body systems, not just one area

Depending on the person, lupus may affect the:

- Joints
- Skin
- Kidneys
- Heart
- Lungs
- Blood vessels
- Blood cells
- Nervous system
- Brain

There are five primary types of lupus:

- Systemic lupus erythematosus, most common form of lupus
- Lupus nephritis, a serious type of lupus that causes inflammation in the kidneys
- Cutaneous lupus, a form of lupus limited to the skin
- Medication-induced lupus, a lupus-like disease caused by certain prescription drugs
- Neonatal lupus, a rare disease that affects infants of women with certain antibodies
- that can be seen in lupus

Lupus affects everyone differently. Some people experience relatively mild disease that primarily affects the skin and joints. Others may develop more serious complications involving major organs such as the kidneys, lungs, heart, or nervous system. Your doctor or specialists will develop a treatment plan based on your individual symptoms and which organs are affected.

Although for now lupus is a lifelong disease, advances in treatment and monitoring have dramatically improved outcomes. Many people living with lupus can work, raise families, pursue education, and participate fully in their communities..

Why is lupus called “the disease of a thousand faces”?

No two people experience lupus the same way.

One person may experience severe fatigue and joint pain. Another may develop skin rashes and kidney disease. A third person may experience symptoms affecting the nervous system or blood cells.

Symptoms can also change over time. A person who initially experiences joint symptoms may later develop skin manifestations or kidney involvement. Disease activity may increase and decrease over months or years. Disease activity refers to how active lupus is in your body at a given time. When disease activity is low, you may have few or no symptoms. When disease activity increases, inflammation becomes more active and symptoms may worsen, resulting in what is known as a flare.

This variability is one reason lupus can be difficult to diagnose and manage.

Common symptoms of lupus include:

- Fatigue
- Joint pain and stiffness
- Joint swelling
- Skin rashes
- Sensitivity to sunlight (photosensitivity)
- Hair loss
- Mouth or nose ulcers
- Fever
- Brain fog or difficulty concentrating
- Headaches
- Chest pain
- Shortness of breath

Some symptoms are visible to others. Many are not.

The unpredictable nature of lupus often adds to uncertainty and frustration. People may feel well one day and significantly worse the next, making it difficult to plan activities, work, carry out family responsibilities, or go to social events.

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Understanding fatigue

Many people think lupus is mostly a disease of joint pain or skin rashes. But people living with lupus often identify fatigue as one of the most difficult symptoms to manage. Lupus fatigue is not simply feeling tired after a busy day. It can be profound, persistent, and difficult to predict. Some people describe it as feeling physically and mentally drained, even after a full night's sleep.

Fatigue may result from:

- Disease activity and inflammation
- Pain
- Sleep disturbances
- Anxiety or depression
- Medication side effects
- Other health conditions

Fatigue can affect work, school, relationships, physical activity, and quality of life. It is also one of the symptoms that others may have difficulty understanding because it is largely invisible.

The impact of fatigue was reflected strongly in ACE's National Survey on Lupus in Canada. People described fatigue affecting their ability to work, care for family members, participate in social activities, exercise, attend school, and complete household responsibilities. Many reported that even routine daily activities could require significant recovery time. Survey findings also showed that lupus frequently limits participation in physical activity and contributes to broader challenges with daily functioning and quality of life.

Understanding and managing fatigue will be discussed in greater detail in Lesson 4.

Remember

Lupus fatigue is different from ordinary tiredness. It may affect your ability to work, exercise, care for family members, or enjoy daily activities, even after a good night's sleep.

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Lupus and arthritis

Joint symptoms are among the most common manifestations of lupus.

Many people living with lupus experience arthritis, joint pain, stiffness, swelling, or reduced mobility. The hands, wrists, knees, ankles, and feet are commonly affected.

Unlike osteoarthritis, which results from wear and tear on joints over time, lupus-related arthritis is caused by inflammation.

For some individuals, joint symptoms are among the earliest signs of disease. Because arthritis symptoms occur in many other conditions, including rheumatoid arthritis and psoriatic arthritis, diagnosis is not always straightforward.

Understanding the connection between lupus and arthritis can help people better recognize symptoms and communicate changes to their healthcare team.

What is lupus nephritis?

One of the most serious complications of lupus is lupus nephritis, which occurs when lupus causes inflammation in the kidneys.

The kidneys help filter waste products and excess fluid from the blood. When lupus affects the kidneys, damage can occur gradually and sometimes without obvious symptoms. This is why regular monitoring is so important.

Health care providers often use one or more of the following to identify kidney involvement as early as possible:

- Blood tests
- Urine tests
- Blood pressure measurements
- Kidney imaging or biopsies when necessary

Early detection and treatment can significantly reduce the risk of permanent kidney damage.

Because kidney disease can sometimes develop silently, routine monitoring remains important even when a person feels well.

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Understanding flares

One of the defining characteristics of lupus is that disease activity often changes over time. For people living with SLE, a flare occurs when disease activity increases and symptoms worsen. Flares may affect the joints, skin, kidneys, or other organs, depending on which parts of the body are involved. During a flare, a person may experience increased fatiguae, joint pain, swelling, skin rashes, fevers, or other symptoms.

Periods when disease activity is well controlled and symptoms improve are often referred to as remission.Remission means lupus is quiet and causing few or no symptoms. Some people remain in remission for long periods, while others continue to experience occasional flares.

Learning to recognize changes in symptoms is an important skill for people living with lupus. Early recognition of a flare can help people seek medical advice promptly and potentially prevent complications.

Not all flares are severe. Some may involve relatively mild symptoms, while others may require urgent medical attention.

Understanding how to recognize and respond to flares will be explored further in Lesson 2.

Did You Know?

Many people living with lupus experience periods when their disease is quiet and symptoms improve, followed by periods when symptoms become more active. Learning to recognize these changes can help you seek care early and may reduce the risk of complications.

Get the care you need sooner

Reduce the risk of complications

Better manage your symptoms

Improve your quality of life

Stay in control of your health

Creating a flare plan

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The lupus patient journey

Although every person's experience is unique, many people living with lupus encounter similar challenges.

These may include:

- Searching for answers before diagnosis
- Learning about a complex disease
- Navigating specialist care
- Understanding treatment options
- Managing symptoms that are often invisible to others
- Balancing work, school, family, and caregiving responsibilities
- Coping with uncertainty about the future

The good news is that lupus care continues to improve. Earlier diagnosis, better monitoring strategies, and new treatment options are helping many people achieve improved disease control and quality of life.

Education is an important part of that process.

By understanding your disease, tracking symptoms, preparing for appointments, asking questions, and participating in treatment decisions, you can become an active and informed partner in your care.

Questions for Your Doctor or Specialist:

- ☑ What type of lupus do I have?
- ☑ Which parts of my body are currently affected?
- ☑ What symptoms should I monitor?
- ☑ What should I do if I think I am having a flare?
- ☑ How can I recognize the warning signs of a flare?
- ☑ Are there any lifestyle changes that may help me manage my lupus?

TIP: Write down your questions and bring them to your appointments. It can help you feel more prepared and make the most of your time.

Your questions matter. Open communication helps you and your healthcare team make the best decisions together.

Important Learning Points from Lesson 1

1 **Lupus is a chronic autoimmune disease** that can affect many organs and systems throughout the body.

2 **There are five types of lupus:** Systemic lupus erythematosus (SLE), Lupus Nephritis, Cutaneous lupus, Drug-induced lupus, and Neonatal lupus.

3 **Lupus symptoms can be different** from one person to another and can change over time. This makes diagnosis and disease management challenging.

4 **Fatigue, joint pain, arthritis, and unexpected flares** are among the most common and disruptive challenges experienced by people living with lupus.

Looking Ahead to the Next Lesson

Understanding lupus is the first step in managing the disease. Equally important is learning how lupus is diagnosed and monitored, recognizing when symptoms change, and knowing when to seek medical advice. In the next lesson, we'll explore the tests used to diagnose and monitor lupus, how to recognize flares, and when it's important to contact your healthcare team.

In the next lesson, you will learn about:

- **Tests used to diagnose and monitor lupus**
- **How to recognize flares and symptom changes**
- **When it's important to seek medical advice**
- **When and how to contact your healthcare team**

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