



Lupus fact sheet

What is lupus?

Lupus is a **chronic autoimmune disease** that can affect any part of the body. An autoimmune disease is when the immune system attacks healthy cells, causing inflammation. The immune system cannot tell the difference between the body's own healthy cells and foreign invaders.

Who is at risk for lupus?

Lupus can affect anyone, regardless of their age and gender. However, lupus is most common in **women** of childbearing age and most often diagnosed between the **ages of 15-44**. Additionally, **Latinas** are **2-3** times more likely to have lupus compared to White women.



What are periods of remission and flare?

When people have lupus they experience changes in their symptoms, called remissions and flares.



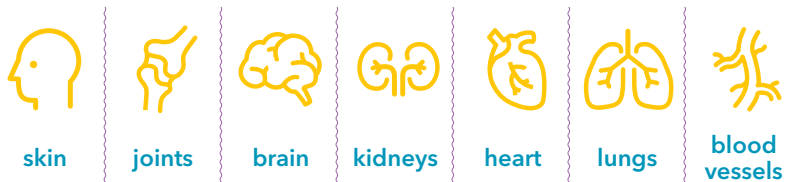
Remission is when a person with diagnosed lupus is feeling well and the immune system is not attacking the body.



Flare is when the immune system attacks the body and causes inflammation. A person with lupus will feel sick from their lupus.

What are the signs and symptoms of lupus?

Lupus can affect any part of the body including



Lupus symptoms may resemble other symptoms of other illnesses, making it hard to diagnose.

Common signs and symptoms

- Feeling very tired
- Losing weight
- Fever
- Swelling in the joints
- Pain in joints and muscles
- Rash on the face shaped like butterfly
- Rashes on the body
- Shortness of breath

Less common signs and symptoms

- Headaches
- Dizziness
- Confusion
- Seizures

What are common lupus treatments?

Lupus treatments are unique to each person with lupus. Lupus treatments generally consist of **medication and maintaining a healthy lifestyle**. Some of the common medications used by doctors to treat lupus include non-steroidal anti-inflammatory drugs like Advil, anti-malarial drugs, corticosteroids like prednisone, and immunosuppressive drugs.

Lifestyle changes that may help manage lupus include:



Getting rest



Exercising



Sun protection



Eating healthy



Avoiding tobacco



Medical visit

If you or someone you know suspects lupus, it is best to make a list of symptoms you are experiencing including the frequency of symptoms and potential triggers. Next, schedule an appointment with your medical provider and discuss your symptoms with him/her.



Verifying online resources



Searching for online lupus resources is a great way to support your clients, but it's important to be aware of where the information is coming from and to assess its validity. Be sure to verify your online resources before sharing information with your community.

Who is the author?

Reliable sources are written by someone with credentials, such as professional experience or a degree appropriate to the topic.

For example, if you want to direct patients to additional information about how to manage a lupus flare, an appropriate author may be a rheumatologist.

Government agencies, like the Center for Disease Control and Prevention, are reliable sources that may not list individual authors.

Is the source current?

Scientific information, including medical information, may change as new research is published. Ensure that you have the latest available information. Websites sometimes have a copyright date or a "last updated" or "last modified" date. These dates are often located at the bottom of the home page. Any source that is more than three years old is likely out of date.

Does the source have citations?

In general, sources with citations suggest that the information is based on research. A citation in the text can be in parentheses like **(Fairweather and Rose, 2004)** or appear as superscripted number¹ with a corresponding full citation at the bottom of the page or the end of the document. These citations mean that the source is backed by research and is not just one person's opinion.

What is the source's goal for writing?

Sources that are emotionally or financially connected to the subject may not be scientifically based. For example, a patients' blog devoted to how to manage lupus symptoms will feature personal experiences rather than current information based on research. Someone selling supplements for lupus may not be objective.

Keywords to search online

Keyword...



- › Lupus and Latinas
- › Lupus specialist in "city name"
- › Lupus and mental health
- › Lupus support groups in "city name"
- › Lupus treatment
- › Lupus signs and symptoms
- › Lupus awareness



Provider, organization, and resource tracking sheet

Use this tracking sheet to keep track of medical providers, organizations and online lupus resources available to your community.

Medical Providers

Name	Specialty	Phone Number	Address	Notes (hours of operation, insurance information, etc.)
	Primary Care Doctor			
	Rheumatologist			

Organizations

Name	Services Offered	Phone Number	Address	Notes



Provider, organization, and resource tracking sheet (continued)

Online Resources			
Name	Website	Information Provided	Notes
American College of Rheumatology's (ACR) Lupus Initiative	www.thelupusinitiative.org	Information in English and Spanish for providers, educators, students, and patients. Offers tools including a symptom tracker for patients	
Hablemos de Lupus	www.hablemosdelupus.org	Offers information and videos in Spanish about different lupus related topics including: <ul style="list-style-type: none">➤ Women, children, and men with lupus➤ Lupus and the circulatory system	
Center for Disease Control and Prevention (CDC)	www.cdc.gov	Offers information in English and Spanish about managing lupus, pregnancy and lupus, and information on organizations that offer resources.	CDC is a government agency



Tracking signs and symptoms

List symptoms you experienced, the date you experienced the symptom, describe what you experienced, and make note of anything you think may have triggered the symptom. Take this tracking sheet with you to all your medical appointments. Tracking your symptoms over time can help you and your doctor manage your symptoms.

Date	Symptoms	Notes (triggers, time of day, etc)



1. Are there any treatments I can use to help manage my symptoms?
2. Are there any other medical providers that I should see about my symptoms?
3. _____
4. _____
5. _____
6. _____



Lupus support assessment tool

Use this handout to assess the needs of a client with suspected or diagnosed lupus. Ask them the following questions.

Have you been diagnosed with lupus by a medical provider?

• If client answers **no**, continue to Part A.

• If client answers **yes**, continue to Part B.

Part A: Client who has not been diagnosed with lupus

	Yes	No
1. Are or have you ever experienced any of the common lupus symptoms? If client answers no, discontinue the assessment.	<input type="checkbox"/>	<input type="checkbox"/>
2. Are you taking any medications to manage your symptoms?	<input type="checkbox"/>	<input type="checkbox"/>
3. Do you have a primary care provider you see for regular care?	<input type="checkbox"/>	<input type="checkbox"/>
4. Do you have a treatment plan to manage your symptoms?	<input type="checkbox"/>	<input type="checkbox"/>
5. Do you have health insurance?	<input type="checkbox"/>	<input type="checkbox"/>
6. Do you know the rights you have regarding your medical care?	<input type="checkbox"/>	<input type="checkbox"/>

If client responds "Yes" to questions 1 or 2 encourage the client to make a list of their symptoms including frequency, triggers, and medications.

If client responds "No" to questions 3 to 6, provide information to a local healthcare provider including contact information to reach the provider and information about health insurance, payment options and /or patient rights. Additionally, address any barriers that may prevent the client from receiving care.

Part B: Client who has been diagnosed with lupus

	Yes	No
1. Are you taking any medications to manage your symptoms?	<input type="checkbox"/>	<input type="checkbox"/>
2. Do you have a primary care provider you see for regular care?	<input type="checkbox"/>	<input type="checkbox"/>
3. Do you have a rheumatologist that you see regularly?	<input type="checkbox"/>	<input type="checkbox"/>
4. Do you have a treatment plan to manage your symptoms?	<input type="checkbox"/>	<input type="checkbox"/>
5. Do you have health insurance?	<input type="checkbox"/>	<input type="checkbox"/>
6. Are you aware of the rights you have regarding your health care?	<input type="checkbox"/>	<input type="checkbox"/>

Ask all clients from Part A and Part B

Ask client to rate each question on a scale of 1 to 5

	Circle one				
	1=never			5=all the time	
7. Do you receive support from an organization or social support group?	1	2	3	4	5
8. Do you receive support from your family and friends?	1	2	3	4	5
9. Do you have coping skills to help manage your feelings and symptoms?	1	2	3	4	5

If a client rates questions 7 to 9 between 1 and 3, provide information to a local healthcare provider including contact information to reach the provider and information about health insurance or payment options. Additionally, address any barriers that may prevent the client from receiving care.

Questions 7 to 8 - If client rates to at least one question between 1 and 3, provide information and support on local resources, how to communicate with family and friends, and identifying coping skills.





Patient rights

Everyone who visits a healthcare provider has patient rights under HIPAA. HIPAA stands for Health Insurance Portability and Accountability Act, and it is a law that protects patients' health information through confidentiality requirements. HIPAA means that health care providers cannot disclose a person's health information without his/her consent.

It is important for patients to know their rights when they are preparing for or attending visits with medical providers, so they can feel in control of their health and the care that they are receiving.



- Patients have the right to ask questions and for clarification about their health and medications.
- Patients can ask their doctor or pharmacist questions about their medication.
- Patients have the right to privacy and confidentiality.
- Patients' medical records and conversations with their doctor are confidential.
- Patients have the right to contribute to making decisions about their treatment. It is the patient's right to suggest different treatment options or ask their doctor about different options.
- Patients can refuse treatment if they do not agree with the course of treatment that the doctor suggests.
- Patients have the right to see another doctor for a second opinion. If the patient is unsatisfied with his/her diagnosis, treatment plan, or quality of care, he/she can find another doctor to receive another opinion.
- Patients have the right to request copies of their medical records. They have the right to all their medical records and can ask their doctor for them at any time. This includes lab results or testing records.
- Patients have the right to request an interpreter if they prefer having important conversations in another language.

