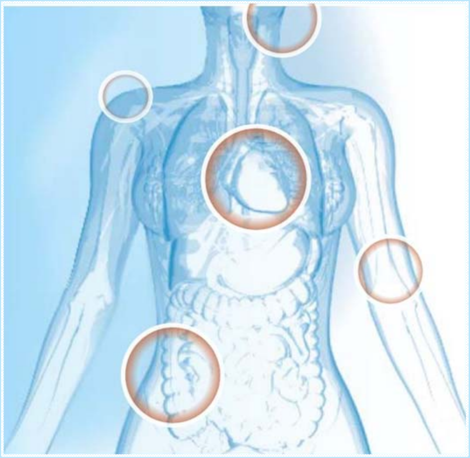
Managing Your Lupus: How Can **You** Take a **More** Active Role?

RNS RHEUMATOLOGY NURSES SOCIETY™



Us in Lupus
Power against lupus

gsk

What Are We Going to **Talk** About?

1. The **immune system** basics and systemic lupus erythematosus (SLE or just “**lupus**”)
2. The importance of taking an active role in **managing your lupus**
3. The **resources** that can help you monitor your symptoms and communicate with your healthcare team

Chapter 1

The Immune System and **Lupus**

Us in Lupus

Power against lupus

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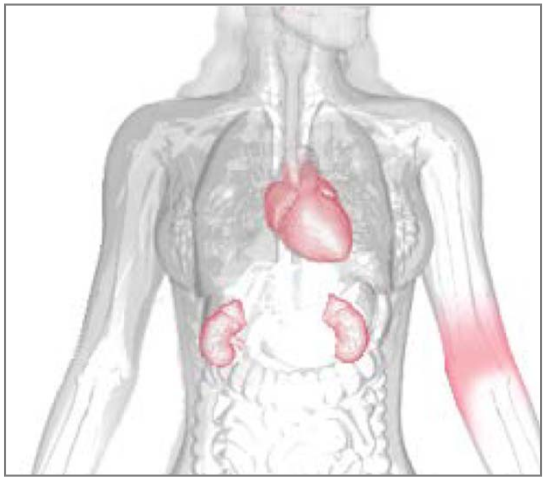
What Is **Lupus**?

- Lupus:
  - Occurs when your body's immune system—the system that fight off viruses and bacteria—attacks its own healthy tissues[1,2]
    - This "autoimmune" activity can cause inflammation, pain, and damage in various parts of the body[1]
  - Is called "chronic" because the signs and symptoms lasts for years[1]
  - Is characterized by flares and remissions—periods during which you may feel worse, and then better[1,2]
- Lupus can be considered a "fingerprint disease"—it's unique in every person[2]



1. *What is lupus?* Lupus Foundation of America Web site. http://www.lupus.org/answers/entry/what-is-lupus. 2015. Accessed August 17, 2015.
2. *Lupus: A Patient Care Guide for Nurses and Other Health Professionals.* 3rd ed. Bethesda, MD: National Institute of Arthritis and Musculoskeletal and Skin Diseases; 2006. NIH publication 06-4262.

There Are **Different Types** of Lupus[1]

Systemic lupus erythematosus or SLE *(or just "lupus")*

- Can affect nearly every part of the body

Discoid lupus *(or cutaneous lupus)*

- Affects only the skin

Drug-induced lupus

- Certain prescription medications can cause drug-induced lupus, which usually goes away once the medication is stopped

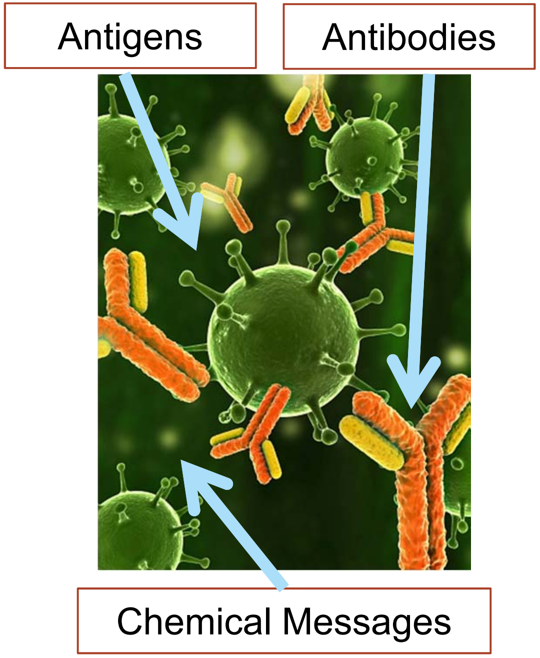
Neonatal lupus

- The newborn of a mother who has lupus may develop a rash or other symptoms that can last for several months before disappearing

1. *Lupus: A Patient Care Guide for Nurses and Other Health Professionals.* 3rd ed. Bethesda, MD: National Institute of Arthritis and Musculoskeletal and Skin Diseases; 2006. NIH publication 06-4262.

Immune System Basics

- Everyone has an immune system[1]
  - The immune system recognizes and fights “foreign” invaders
- A general term for foreign invaders is **antigens**, which includes germs such as bacteria and viruses[1]
- In your immune system[2]
  - **White blood cells** talk to each other by sending **chemical messages to make antibodies**
  - **Antibodies** attach to **antigens** and “mark” them for removal



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1. Cuzzell JL. In: Carter SC, et al, eds. *Core Curriculum for Rheumatology Nursing.* 1st ed. Greenville, SC: Rheumatology Nurses Society; 2015:159-168. **2.** *Understanding the Immune System: How It Works.* Bethesda, MD: National Institute of Allergy and Infectious Diseases, National Institutes of Health, US Dept of Health and Human Services; September 2003. NIH publication 03-5423.

The Immune System in **Lupus**[1]

- In lupus, the immune system cannot tell the difference between your own body and foreign invaders that are harmful
- Lupus is like an allergic reaction to some parts of your own body
  - Your body is essentially fighting itself
- This reaction leads to inflammation of organs and the signs and symptoms of SLE

[1] **1.** *Lupus: A Patient Care Guide for Nurses and Other Health Professionals.* 3rd ed. Bethesda, MD: National Institute of Arthritis and Musculoskeletal and Skin Diseases; 2006. NIH publication 06-4262.

Who Gets Lupus?

- The cause of lupus is not known—anyone can get lupus[1]
- In the United States, there are approximately 171,000 individuals currently living with lupus[2,3]
- Women between 15 and 44 years of age are more likely to get lupus[2,3]
- Lupus is more common and severe among nonwhite populations[4,5]
- Lupus may run in families, but most people with lupus do not have a close relative with lupus[1]

1. *Lupus: A Patient Care Guide for Nurses and Other Health Professionals.* 3rd ed. Bethesda, MD: National Institute of Arthritis and Musculoskeletal and Skin Diseases; 2006. NIH publication 06-4262. **2.** Somers EC, et al. *Arthritis Rheumatol.* 2014;66(2):369-378. **3.** Lim SS, et al. *Arthritis Rheumatol.* 2014;66(2):357-368. **4.** *What Is Lupus? Fast Facts: An Easy-to-Read Series of Publications for the Public.* Bethesda, MD: National Institute of Arthritis and Musculoskeletal and Skin Diseases; 2009. **5.** Manzi S. *Cleve Clin J Med.* 2009;76(2):137-142.

Additional **Risk Factors**[1]

- Some factors that increase the chance of someone getting lupus include:

Ultraviolet (UV) rays from the sun or fluorescent lightbulbs

Infections, colds, or other viral illnesses

Cigarette smoking

Hormonal therapy

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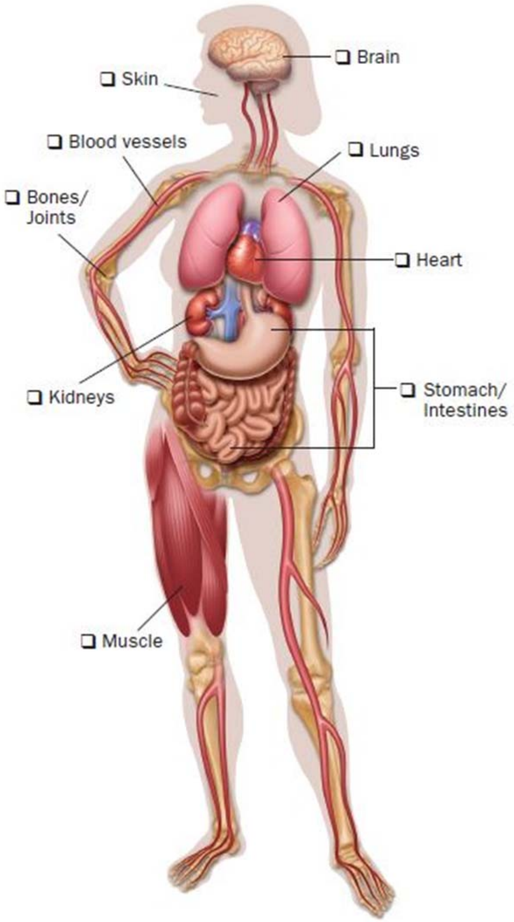
1. *Lupus: A Patient Care Guide for Nurses and Other Health Professionals.* 3rd ed. Bethesda, MD: National Institute of Arthritis and Musculoskeletal and Skin Diseases; 2006. NIH publication 06-4262.

How Lupus **Affects Your Body**[1]

- When your immune system attacks your own body, it can cause damage to many parts of the body
  - As a result, you may have symptoms (discussed later)
- Lupus may affect 1 or more parts of the body
- Lupus can also cause serious problems that you may not see or feel



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[1] *Lupus: A Patient Care Guide for Nurses and Other Health Professionals.* 3rd ed. Bethesda, MD: National Institute of Arthritis and Musculoskeletal and Skin Diseases; 2006. NIH publication 06-4262.

What Are Some of the **Visible Symptoms** of Lupus?

Although symptoms may sometimes disappear, the disease does not go away[1,2]

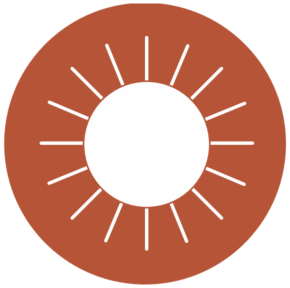
- Symptoms may be different for everyone[1]
- Some of the common visible symptoms are[3]:

Swelling of joints

Fever over 100°F

Hair loss

Nose or mouth sores



Skin rashes after sun exposure

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1. *Lupus: A Patient Care Guide for Nurses and Other Health Professionals.* 3rd ed. Bethesda, MD: National Institute of Arthritis and Musculoskeletal and Skin Diseases; 2006. NIH publication 06-4262. **2.** Heinlen LD, et al. *Arthritis Rheum.* 2007;56(7):2344-2351. **3.** Cervera R, et al. *Medicine*. 1993;72(2):113-124.

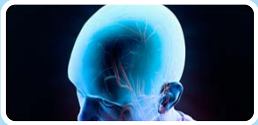
Some Examples of the **Invisible Effects** of Lupus[1]

- Lupus can also cause serious problems that you may not see, such as:

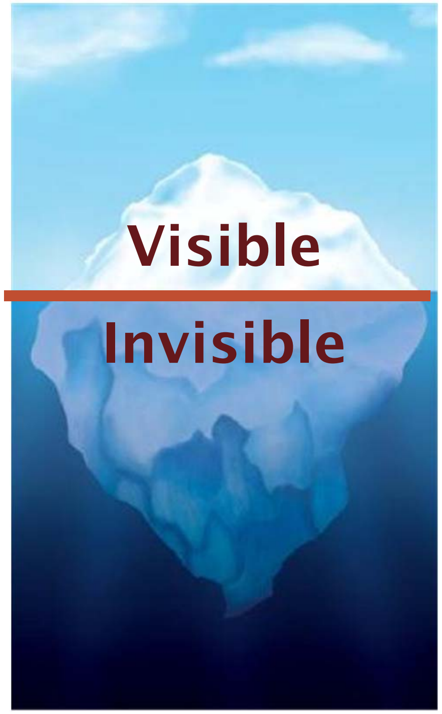
Inflamed **kidneys** may not work correctly

Inflamed linings of the **heart** and **lungs** may cause chest pain

Effect on the **brain** make it difficult to think clearly



Fatigue



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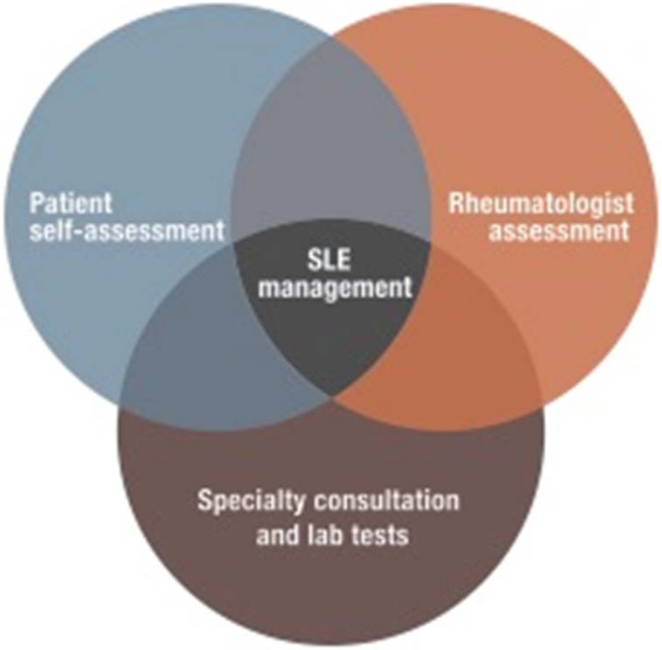
[1] *Lupus: A Patient Care Guide for Nurses and Other Health Professionals.* 3rd ed. Bethesda, MD: National Institute of Arthritis and Musculoskeletal and Skin Diseases; 2006. NIH publication 06-4262.

Why Is It Important to **Monitor** Your Symptoms?

- Active disease
  - The presence of signs and symptoms known as "**active disease**" is associated with an increased risk of damage to your major organs[1]

- Every symptom matters!
  - You may not think that some symptoms are lupus related, but they may be a sign of lupus-related inflammation that could lead to organ damage

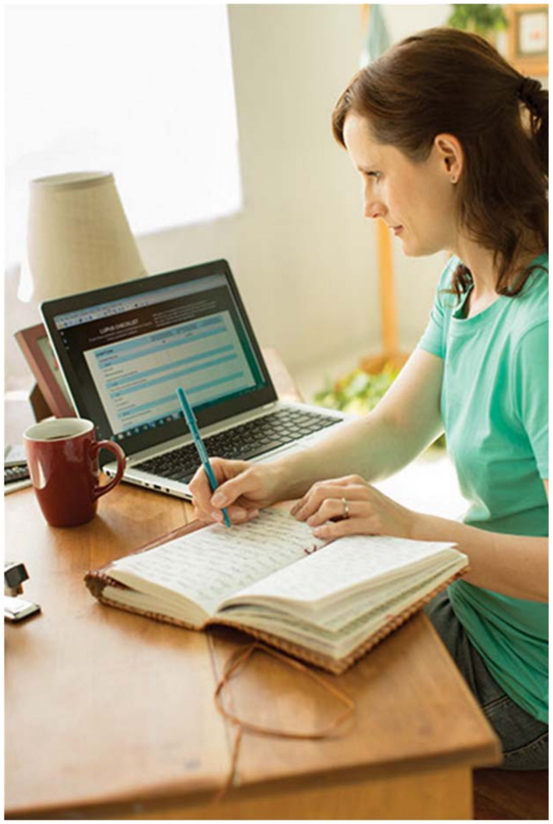
Monitoring symptoms should be a team effort[3]



1. Lopez R, et al. *Rheumatology (Oxford).* 2012;51(3):491-498. **2.** *Lupus: A Patient Care Guide for Nurses and Other Health Professionals.* 3rd ed. Bethesda, MD: National Institute of Arthritis and Musculoskeletal and Skin Diseases; 2006. NIH publication 06-4262. **3.** American College of Rheumatology Ad Hoc Committee on Systemic Lupus Erythematosus Guidelines. *Arthritis Rheum.* 1999;42(9):1785-1796.

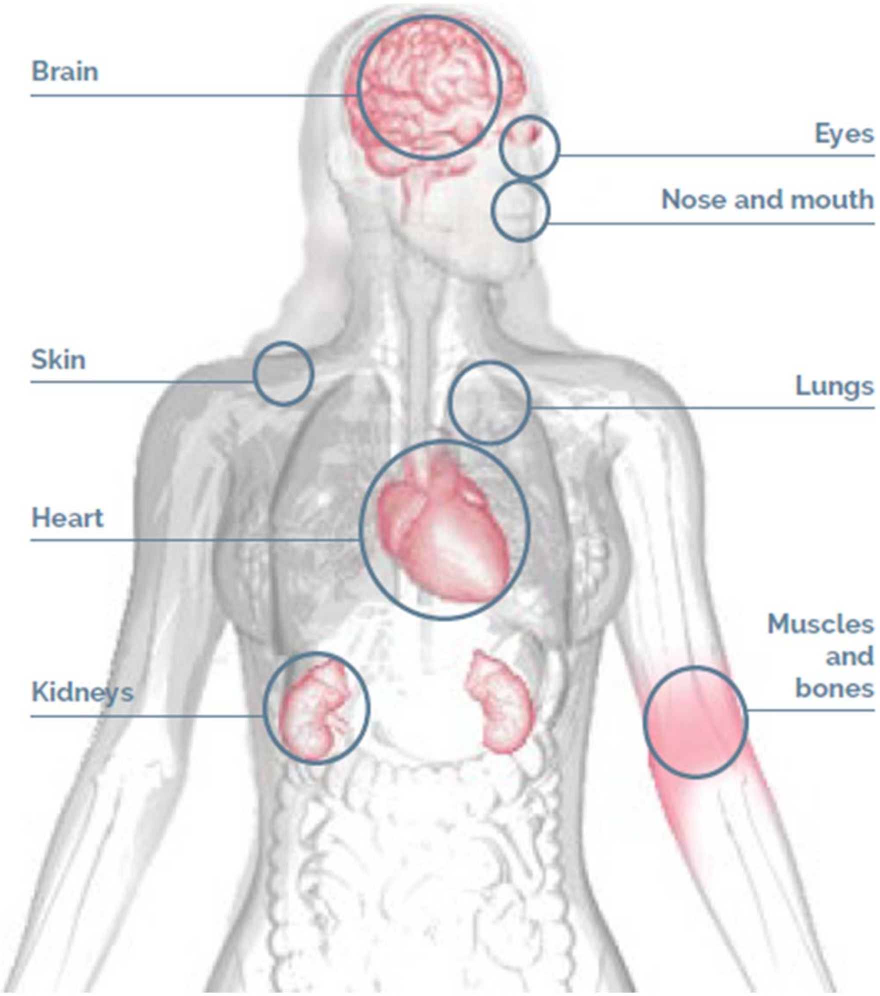
Reflection: Consider **Your Experiences**

Take a moment for some self-reflection



- What symptoms have you experienced?
- What are the areas of the body that most concern you? Why?
- Do you worry about the silent effects eg, inflamed kidneys of lupus?
  - Do you share these concerns with someone?
- Did you know that there are things that you can do to help manage your lupus?

Some Organs That Are **Affected by Lupus**



What Symptoms Should You Be **Looking For?**

Know the symptoms associated with active disease[1]

Skin	• rashes, sensitivities to sun or light, mouth and nose sores, and hair loss[2]
Brain	• seizures, headaches, dizziness, sad thoughts, memory problems, and confusion[2]
Eyes	• dry eyes, eye redness, and some loss of vision[3]

1. van Vollenhoven RF, et al. *Ann Rheum Dis.* 2014;73(6):958-967. **2.** American College of Rheumatology Ad Hoc Committee on Systemic Lupus Erythematosus Guidelines. *Arthritis Rheum.* 1999;42(9):1785-1796. **3.** Sivaraj RR, et al. *Rheumatology (Oxford)*. 2007;46(12):1757-1762.

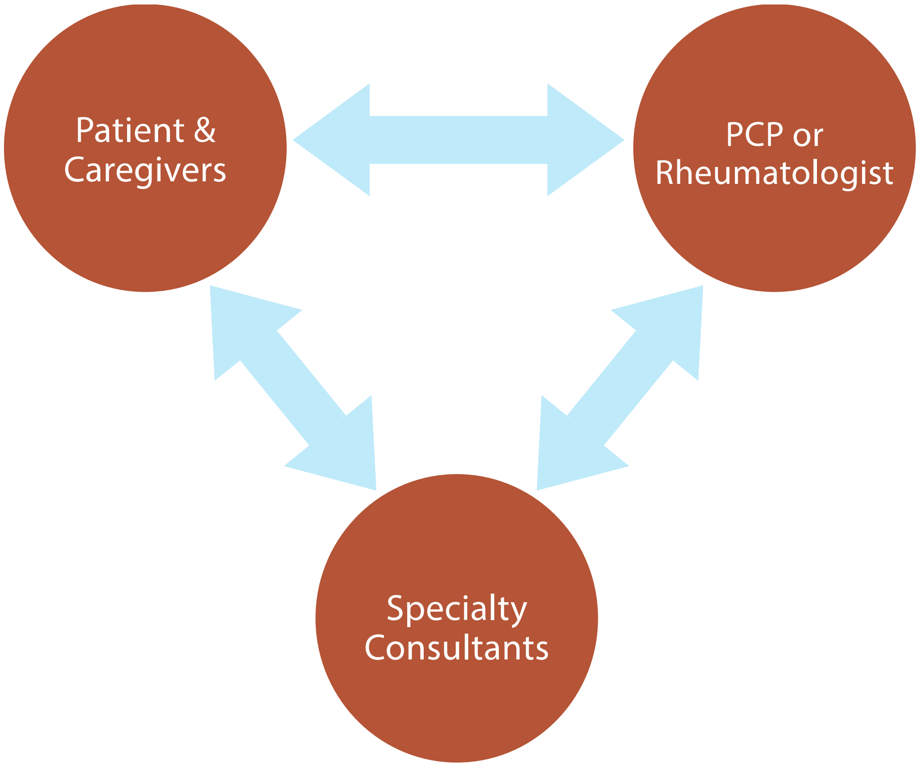
What Symptoms Should You Be **Looking For?** (continued)

Muscles and bones	• muscle weakness, stiffness in joints, and aching muscles[1]
Heart and lungs	• chest pain and difficulty breathing[2]
Kidneys	• swelling of legs and/or feet, and frothy and/or bloody urine[3]
Daily flu-like symptoms	• fever, fatigue, and nausea[3]

1. American College of Rheumatology Ad Hoc Committee on Systemic Lupus Erythematosus Guidelines. *Arthritis Rheum.* 1999;42(9):1785-1796. **2.** Ward MM. *Arthritis Rheum.* 1999;42(2):338-346. **3.** *Lupus: A Patient Care Guide for Nurses and Other Health Professionals.* 3rd ed. Bethesda, MD: National Institute of Arthritis and Musculoskeletal and Skin Diseases; 2006. NIH publication 06-4262.

Routine Monitoring of Your Lupus

- Routine monitoring of symptoms associated with lupus is essential[1]
- Components of routine monitoring should include[1,2]:



Patient & Caregivers

PCP or Rheumatologist

Specialty Consultants

PCP = primary care physician.

1. American College of Rheumatology Ad Hoc Committee on Systemic Lupus Erythematosus Guidelines. *Arthritis Rheum.* 1999;42(9):1785-1796.

2. van Vollenhoven RF, et al. *Ann Rheum Dis.* 2014;73(6):958-967.

Participating in Your Care[1]

- You are a **key component** in assessing your disease activity

Feel empowered to be your own advocate

Promote **open communication** with your healthcare team

Educate yourself and **ask questions**

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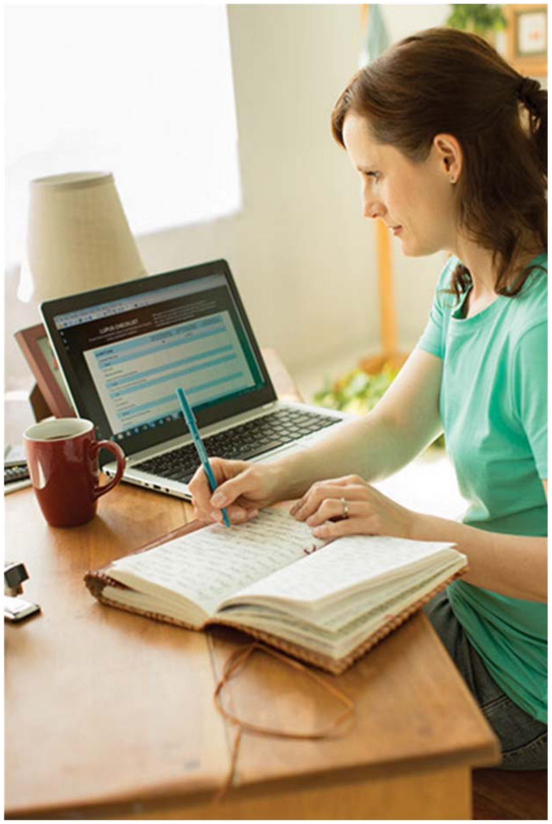
1. van Vollenhoven RF, et al. *Ann Rheum Dis.* 2014;73(6):958-967.

Reflection:
Consider How **You Manage** Your Lupus

Take a moment for some self-reflection

- Think about how you currently manage or track your lupus:
  - What challenges do you face?
- Do you feel like you are taking an active role in disease self-management?
- Are you aware of ways that you can take an active role in disease self-management?



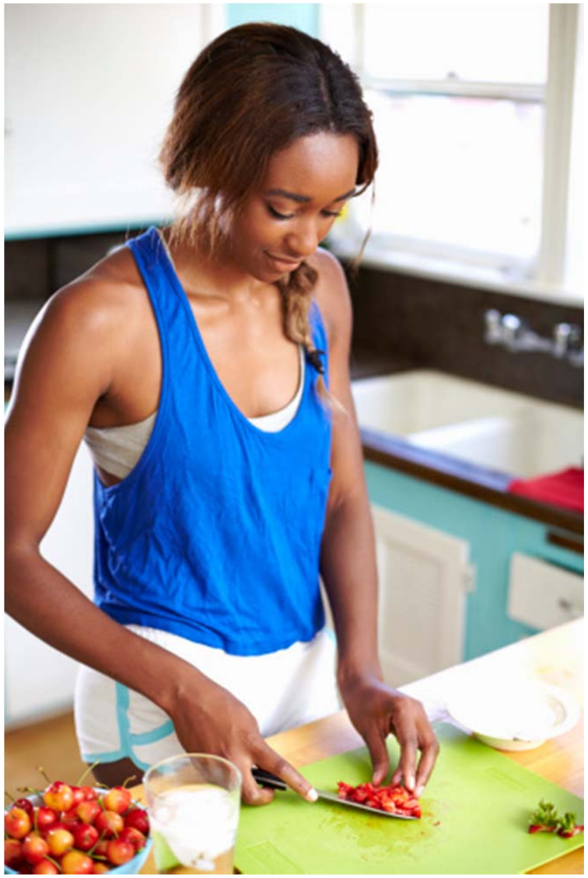
Chapter 2

Managing Your Lupus

Us in Lupus
Power against lupus

You Can Take Control[1]

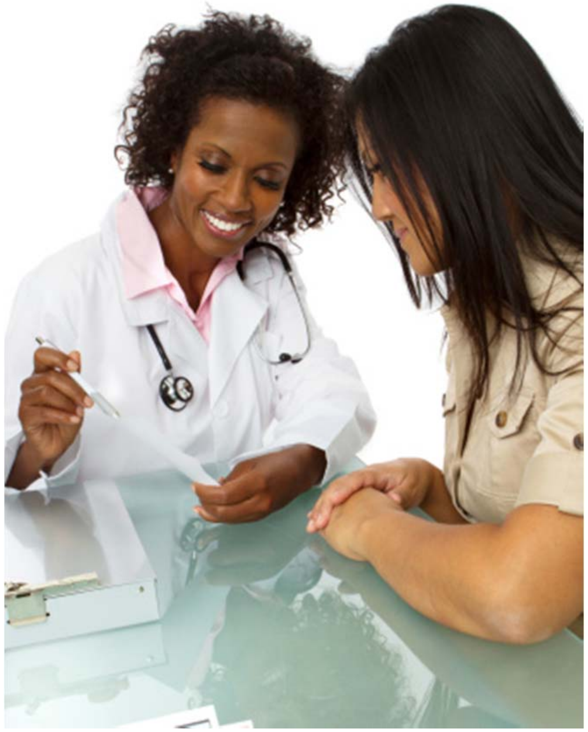
- Eat healthy and stay active
  - Talk with your healthcare team about a heart-healthy diet
  - A healthy diet can also help keep your energy up



[1] *Lupus: A Patient Care Guide for Nurses and Other Health Professionals.* 3rd ed. Bethesda, MD: National Institute of Arthritis and Musculoskeletal and Skin Diseases; 2006. NIH publication 06-4262.

You Can Take Control[1] (continued)

- Listen to your doctor’s instructions
  - Work with your healthcare team to develop a management plan that is right for you
  - Tell your healthcare team if a routine is not working for you or if you are having trouble sticking to a management plan
  - Together, you may be able to find a solution that works for you



1. *Lupus: A Patient Care Guide for Nurses and Other Health Professionals.* 3rd ed. Bethesda, MD: National Institute of Arthritis and Musculoskeletal and Skin Diseases; 2006. NIH publication 06-4262.

You Can Take Control[1] (continued)

- Be sun smart
  - Try to limit your exposure to UV rays when outdoors
  - Wear a hat, long sleeves, pants, and sunscreen

1. *Lupus: A Patient Care Guide for Nurses and Other Health Professionals.* 3rd ed. Bethesda, MD: National Institute of Arthritis and Musculoskeletal and Skin Diseases; 2006. NIH publication 06-4262.

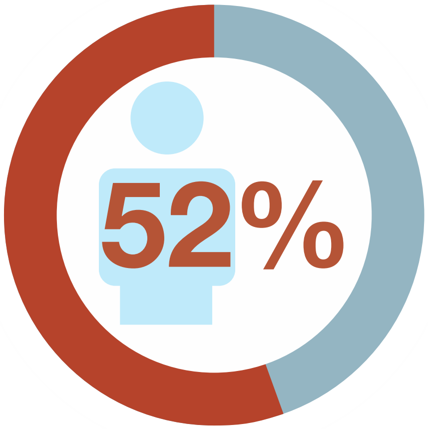
You Can Take Control[1] (continued)

- Involve friends and family
  - They are a great source of support, so let them know how they can help
- Ask for help
  - Even if you need emotional encouragement, help running errands, or a second set of eyes and ears at a doctor's appointment
  - Don't be afraid to lean on those closest to you

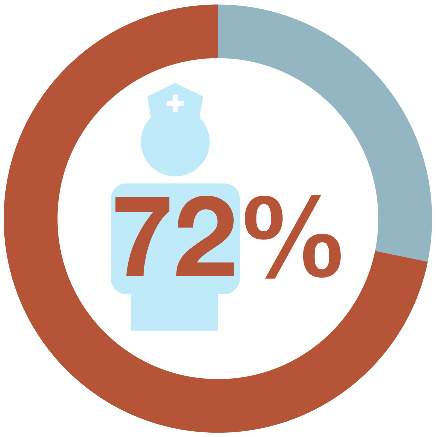
[1] *Lupus: A Patient Care Guide for Nurses and Other Health Professionals.* 3rd ed. Bethesda, MD: National Institute of Arthritis and Musculoskeletal and Skin Diseases; 2006. NIH publication 06-4262.

Differences in Communication[1]

- In 2011, a survey* was conducted of 957 members of the lupus community, including patients, supporters, and rheumatologists
- It revealed communication gaps about symptoms between physicians and patients



52% of patients reported that they minimized their symptoms when they talked to physicians



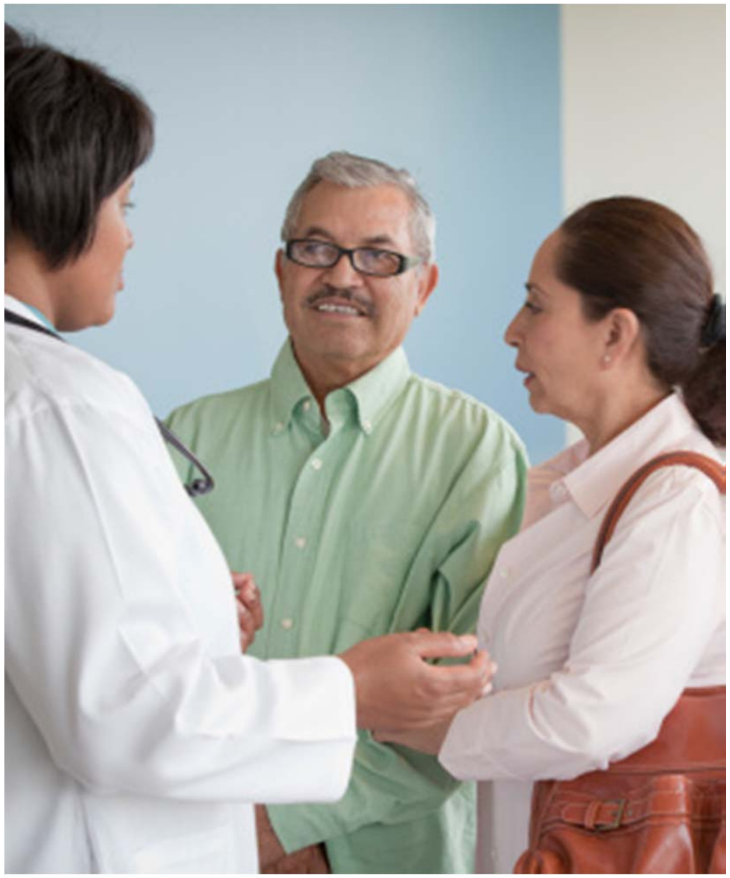
72% of physicians were unaware that patients tended to underreport their symptoms

*Data from the 2011 National Burden of Lupus survey funded and developed by GSK. Data on file, GlaxoSmithKline, 2011.

[1] *Lupus: A Survey Among SLE Patients, Physicians, and Supporters.* New York, NY: GfK Roper Public Affairs and Corporate Communications; October 2011.

Communication **Challenges**

- One of the challenges in managing lupus is the lack of communication between patients, caregivers, and families[1]
- Remember, the first step in taking control of lupus is sharing all of your symptoms with your healthcare team and with your loved ones[2]
- Communication is the best way to ensure that you get the support you need[3]



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Why Is **Communication** So Important?

> “*I have seen these challenges reflected in my clinical practice. It is critical that patients and physicians understand the importance of clear communication because it has implications for disease management. For example, patients may not mention low-level disease symptoms as they may consider it a normal part of living with lupus. However, low-level disease activity can still cause organ damage and may represent a missed opportunity for identifying a flare and instituting early intervention.*”

Anca Askanase, MD, MPH

Dr. Askanase received a fee for her participation in this program

Patient Care Insights™

Systemic Lupus Erythematosus (SLE): Understanding and Addressing Patient Needs

FEATURED EXPERT

ANCA D. ASKANASE, MD, MPH
Clinical Director
Lupus Center
Director of Rheumatology Clinical Trials
Columbia University Medical Center
New York, New York

TOPIC HIGHLIGHTS

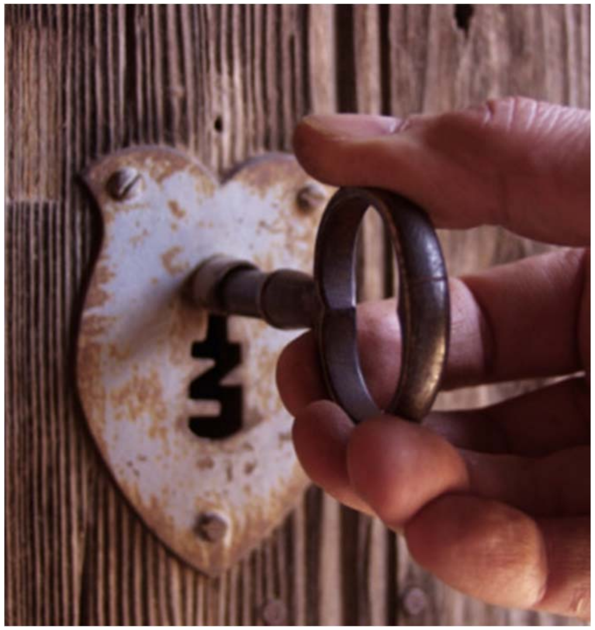
- SLE has a considerable impact on patients, including their psychosocial well-being, interpersonal relationships, quality of life, productivity, and healthcare utilization.
- Due to the complexity of SLE management, healthcare providers may need to coordinate additional patient care and support from a multidisciplinary team.
- Survey data revealed a serious gap between what patients experience and what they are willing to share with others, including their rheumatologists.
- Facilitating positive physician-patient interactions is an important part of SLE management. Such interactions are associated with patients being more satisfied with their management plan, feeling that their SLE is well controlled, expressing more favorable perception of current health, and having more hopefulness about their future health.
- To facilitate effective communication about SLE, it is important that patients be able to help physicians distinguish coincidental but unrelated symptoms from the symptoms of a flare.
- The American College of Rheumatology (ACR) guidelines recommend lifelong monitoring of disease activity and chronic comorbidities.
- A range of clinical issues must be considered when managing patients with SLE, including fatigue, neuropsychiatric syndromes, cardiovascular disease, nephritis, and osteoporosis. Damage to major organ systems accrues over time and there is an increased mortality risk.

This promotional program was developed in conjunction with and sponsored by GSK, based on an interview with Anca D. Askanase, MD, MPH.

Dr Askanase received a fee for participation in this program.

Communication Is Key

- Work with your healthcare team
  - Monitoring of lupus should be a team effort[1]
- Shared decisions and open communication are imperative[2]
  - **Open and honest** communication with your healthcare team is an important part of any lupus diagnosis
  - Talk openly, even on topics that you may feel uncomfortable with
  - Your healthcare team is there to support you



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2. van Vollenhoven RF, et al. *Ann Rheum Dis.* 2014;73(6):958-967.

Communication Builds **Relationships**

“…over the years, I’ve learned the importance of building a strong and open relationship with my doctors. It’s so extremely important. I feel so honored to now have a doctor who not only listens to my concerns and has my best interest at heart, but also seems to genuinely care about me and my well-being.”

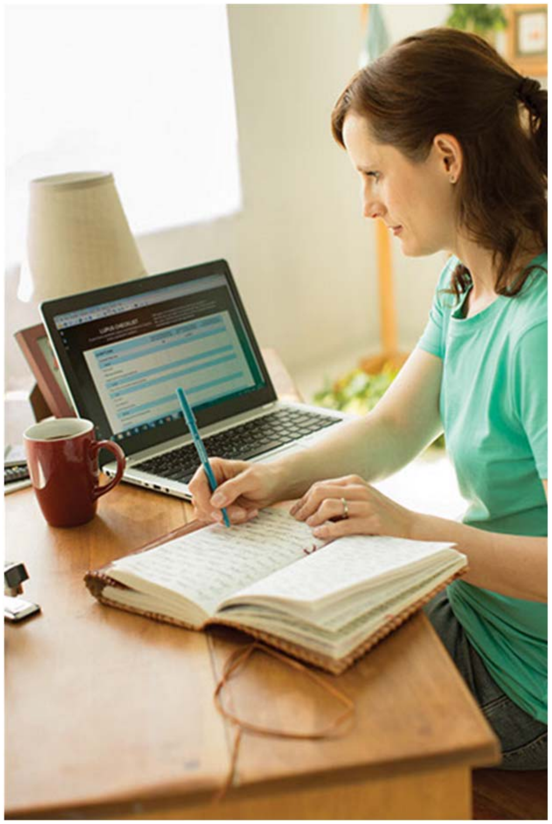
Rena, currently living with lupus

Rena is a paid spokesperson for GSK

Reflection: Consider **Your Interactions** With Your Healthcare Team

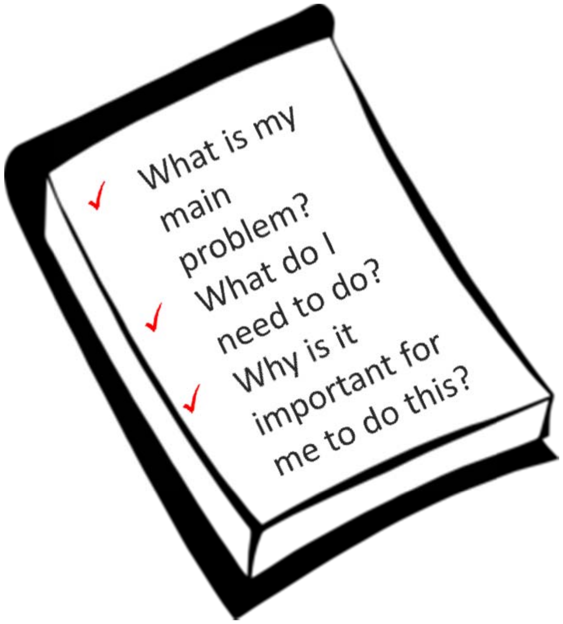
Take a moment for some self-reflection

- What does good communication with your healthcare team look like?
- Think about whether there are symptoms you don’t talk about with your healthcare team.
  If so, why?
- What kind of support and interaction do you want to receive from your healthcare team?
- What ways can you assist your healthcare team in having effective communication?



Tips for **Communicating**

- Report all symptoms, regardless of whether you believe they are lupus related or not[1]
  - Also discuss symptoms that have disappeared
- Bring a list of all the providers you are seeing and all the medications you are taking to every medical appointment[2]
- Follow the "Ask Me 3" Program[3]
  - Questions designed by the National Patient Safety Foundation
- Be informed and stay active in being educated on lupus[1]



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Education Is Important

- **Be informed. Be empowered!**
  - The more you know about lupus, the better you can talk to your healthcare team

- Know **how** your healthcare team monitors your disease
  - Routine blood tests to analyze how your blood is clotting[1]
  - Urine tests, because the kidneys are often affected by SLE
  - Tests for antibodies, such as[2]:
    - Antinuclear antibodies (ANA)
    - Anti-dsDNA

ANA = antinuclear antibody; anti-dsDNA = anti–double-stranded DNA.

1. *Lupus: A Patient Care Guide for Nurses and Other Health Professionals.* 3rd ed. Bethesda, MD: National Institute of Arthritis and Musculoskeletal and Skin Diseases; 2006. NIH publication 06-4262. **2.** Petri M, et al. *Arthritis Rheum*. 2012;64(8):2677-2686.

Keeping Track and Reporting **Accurately** Is Important

- Keep track of all symptoms regularly so that you can report accurately[1]
  - Keep a journal
  - Involve friends and family
  - Use available apps on your mobile devices
  - Have medical records available for your reference

- Share all of these important factors with your healthcare team
  - Do your symptoms change over time?
  - How are they affecting your daily life?
  - Do they prevent you from doing things that you enjoy?
  - Does lupus make you feel isolated, depressed, or frustrated?

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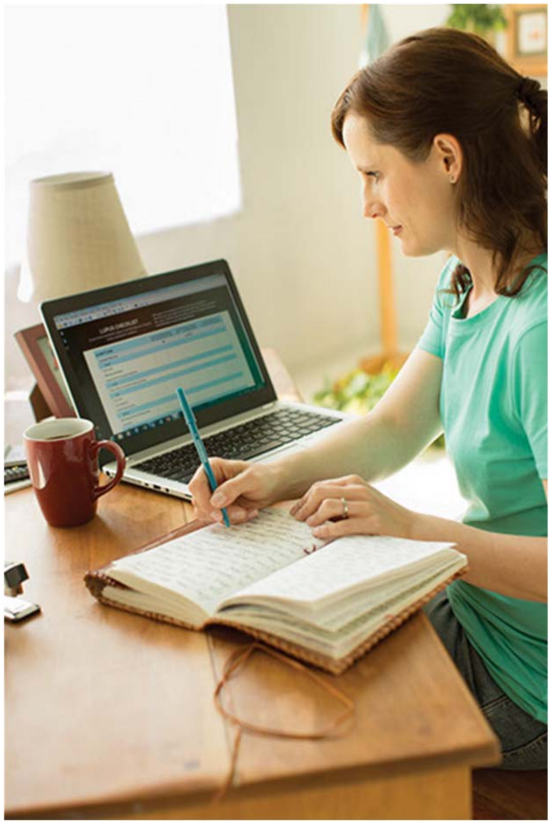
1. American College of Rheumatology Ad Hoc Committee on Systemic Lupus Erythematosus Guidelines. *Arthritis Rheum.* 1999;42(9):1785-1796.

Reflection:
Consider How You **Track** and **Report**

Take a moment for some self-reflection

- How do you keep track of your symptoms?
  - Are you reporting your symptoms accurately?
- Do you forget to report symptoms?
- Are you being honest in reporting?
- Has there been a time that you have not told your healthcare team about a symptom because you thought it was not important anymore?



Chapter 3

Resources for **You**

Us in Lupus

Power against lupus

Where Can You Go for Help?

YOU

Us in Lupus.com Program

Healthcare Team

Friends

Family

Patient Advocacy Groups

Us in Lupus.com Is Here to Help

- **Us** in **Lupus** gives you more than just the facts about lupus
- Designed by GSK, it offers people like you, living with lupus, the skills, tools, and confidence you need to help you face your lupus

Us in Lupus
Power against lupus

Us in Lupus.com Provides Tools

- **Us** in **Lupus** provides important tools to help you prepare for your appointments and learn more about your lupus
  - Lupus Checklist
  - Lupus Impact Tracker™
  - My Lupus Log
  - Lupus Journal
  - Appointment Prep Guide
  - Lupus Dictionary

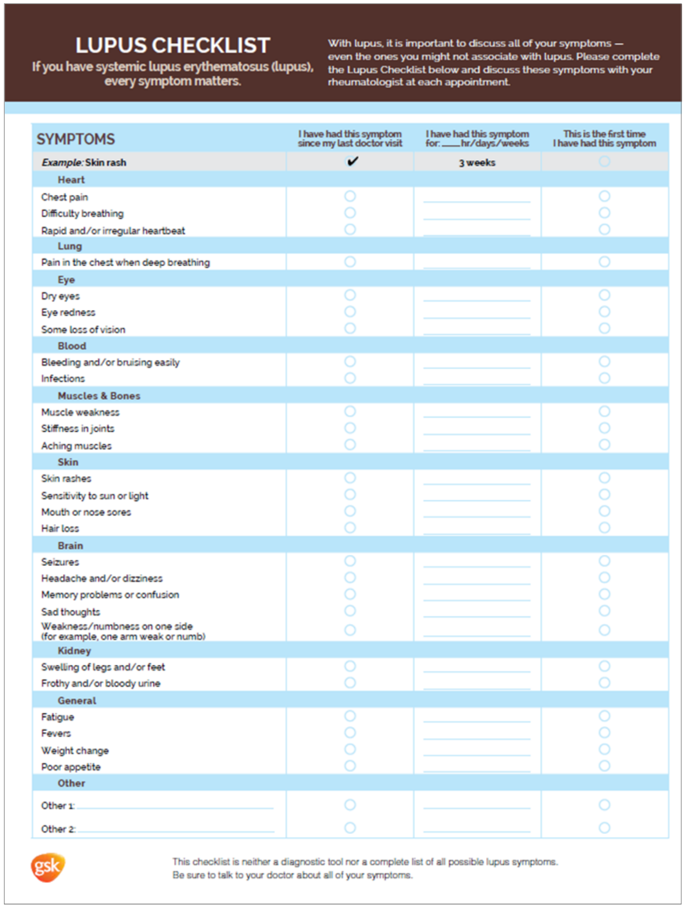
Us in Lupus
Power against lupus

Take advantage of these tools to help you prepare for your appointments and learn more about lupus

Lupus **Checklist**

This checklist helps you to recognize the symptoms and risk factors for lupus

- ✓ Print and record symptoms and other changes to your health
- ✓ Bring the completed checklist to your next medical appointment to spark discussions with your healthcare team
- ✓ To download, simply visit www.usinlupus.com



LUPUS CHECKLIST

If you have systemic lupus erythematosus (lupus), every symptom matters.

With lupus, it is important to discuss all of your symptoms — even the ones you might not associate with lupus. Please complete the Lupus Checklist below and discuss these symptoms with your rheumatologist at each appointment.

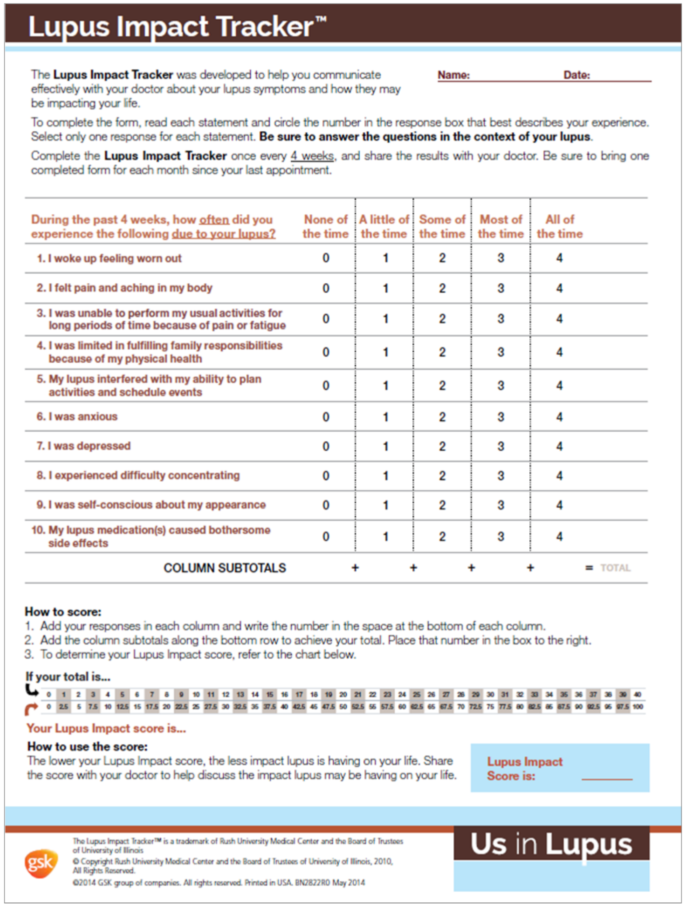
SYMPTOMS	I have had this symptom since my last doctor visit	I have had this symptom for: ____hr/days/weeks	This is the first time I have had this symptom
Example: Skin rash	✓	3 weeks	○
Heart			
Chest pain	○	____	○
Difficulty breathing	○	____	○
Rapid and/or irregular heartbeat	○	____	○
Lung			
Pain in the chest when deep breathing	○	____	○
Eye			
Dry eyes	○	____	○
Eye redness	○	____	○
Some loss of vision	○	____	○
Blood			
Bleeding and/or bruising easily	○	____	○
Infections	○	____	○
Muscles & Bones			
Muscle weakness	○	____	○
Stiffness in joints	○	____	○
Aching muscles	○	____	○
Skin			
Skin rashes	○	____	○
Sensitivity to sun or light	○	____	○
Mouth or nose sores	○	____	○
Hair loss	○	____	○
Brain			
Seizures	○	____	○
Headache and/or dizziness	○	____	○
Memory problems or confusion	○	____	○
Sad thoughts	○	____	○
Weakness/numbness on one side (for example, one arm weak or numb)	○	____	○
Kidney			
Swelling of legs and/or feet	○	____	○
Frothy and/or bloody urine	○	____	○
General			
Fatigue	○	____	○
Fevers	○	____	○
Weight change	○	____	○
Poor appetite	○	____	○
Other			
Other 1: ____	○	____	○
Other 2: ____	○	____	○

This checklist is neither a diagnostic tool nor a complete list of all possible lupus symptoms. Be sure to talk to your doctor about all of your symptoms.

Lupus **Impact** Tracker™

The Lupus Impact Tracker™ is a simple worksheet that can help you determine a rating for how lupus is affecting your life

- ✓ Complete it once every 4 weeks, and share the results with your healthcare team
- ✓ Be sure to bring a completed version of the form for each month since your last appointment
- ✓ To download, simply visit www.usinlupus.com



Lupus Impact Tracker™

The **Lupus Impact Tracker** was developed to help you communicate effectively with your doctor about your lupus symptoms and how they may be impacting your life.

Name: **Date:**

To complete the form, read each statement and circle the number in the response box that best describes your experience. Select only one response for each statement. **Be sure to answer the questions in the context of your lupus**.

Complete the **Lupus Impact Tracker** once every 4 weeks, and share the results with your doctor. Be sure to bring one completed form for each month since your last appointment.

During the past 4 weeks, how often did you experience the following due to your lupus?	None of the time	A little of the time	Some of the time	Most of the time	All of the time
1. I woke up feeling worn out	0	1	2	3	4
2. I felt pain and aching in my body	0	1	2	3	4
3. I was unable to perform my usual activities for long periods of time because of pain or fatigue	0	1	2	3	4
4. I was limited in fulfilling family responsibilities because of my physical health	0	1	2	3	4
5. My lupus interfered with my ability to plan activities and schedule events	0	1	2	3	4
6. I was anxious	0	1	2	3	4
7. I was depressed	0	1	2	3	4
8. I experienced difficulty concentrating	0	1	2	3	4
9. I was self-conscious about my appearance	0	1	2	3	4
10. My lupus medication(s) caused bothersome side effects	0	1	2	3	4
COLUMN SUBTOTALS	+	+	+	+	= TOTAL

How to score:

1. Add your responses in each column and write the number in the space at the bottom of each column.
2. Add the column subtotals along the bottom row to achieve your total. Place that number in the box to the right.
3. To determine your Lupus Impact score, refer to the chart below.

If your total is...

0	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
0	2.5	5	7.5	10	12.5	15	17.5	20	22.5	25	27.5	30	32.5	35	37.5	40	42.5	45	47.5	50

21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40
52.5	55	57.5	60	62.5	65	67.5	70	72.5	75	77.5	80	82.5	85	87.5	90	92.5	95	97.5	100

Your Lupus Impact score is...

How to use the score:
The lower your Lupus Impact score, the less impact lupus is having on your life. Share the score with your doctor to help discuss the impact lupus may be having on your life.

Lupus Impact Score is: ______

Us in Lupus

My Lupus **Log**

Available **free** from the Play Store on any Android device, My Lupus Log lets you:

- Conveniently track lupus symptoms
- Record and monitor how they are affecting you
- Customize your profile
- Learn more about lupus
- Stay focused with alerts and reminders
- Customize functions with step-by-step instructions

Keeping a close eye on your symptoms is part of managing your lupus

My Lupus Log

Headache — On a scale of 0 – 5, (5 being the worst): 0

Joint Pain — On a scale of 0 – 5, (5 being the worst): 1

Joint Swelling — On a scale of 0 – 5, (5 being the worst): 2

Rash — On a scale of 0 – 5, (5 being the worst): 2

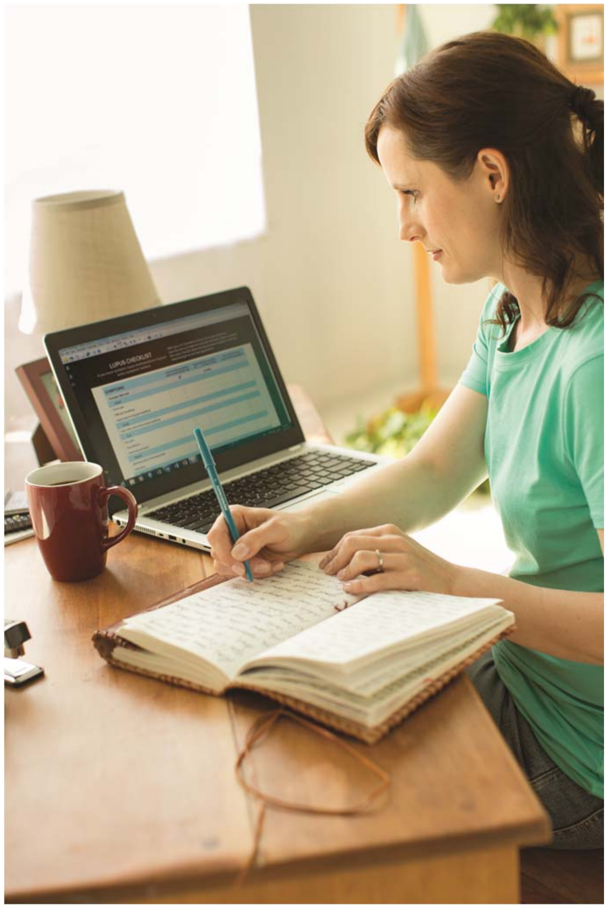
Issues — On a scale of 0 – 5, (5 being the worst): 3

On a scale of 0 – 5, (5 being the worst): 4

Lupus **Journal**

When you're living with lupus, journaling can be a good way to document your thoughts, feelings, symptoms, and any questions you may want to discuss with your healthcare team

✓ Simply sign up at www.usinlupus.com and request your free lupus journal



Appointment **Prep** Guide

This handy checklist can help you make the most of medical visits

- ✓ Read it carefully, and bring it to all of your medical appointments
- ✓ To download, simply visit www.usinlupus.com

Appointment Prep Guide

You live with lupus every day, but you probably see your rheumatologist only once every 3 months or so. With most appointments lasting less than 15 minutes, it's important to make the most of the valuable time you spend with your doctor.

The steps that follow are designed to help you have the power to face your lupus. **Check each one off** as you prepare for your next appointment and you'll be ready to make your time together productive.

☐ **Step 1: Take note of all your symptoms.** Use the **Lupus Checklist** before your appointment to record all your symptoms, even the ones that may not feel like lupus. If you have an Android™ smartphone, you may want to download our free app, **My Lupus Log.** It can help you monitor and track your symptoms. Simply go to the Google Play™ Store and search "My Lupus Log."

☐ **Step 2: Document how lupus is affecting your life.** The **Lupus Impact Tracker™** can be especially helpful in understanding how lupus may be interfering with your day-to-day life. Complete the tracker now, and then plan to complete another one every 4 weeks, so you can begin to see how lupus is affecting you over time.

☐ **Step 3: Get ready.** One of the most important things to remember is to get ready well ahead of time. How exactly should you do that? Start by finding the date of your next appointment on your calendar. Then, find the date that is **3 weeks before your appointment.** Circle that date as your get-ready starting point.

☐ **Step 4: Choose your appointment buddy.** Take a trusted friend or family member to help you with important tasks during your appointment so you can be free to talk to your doctor. Ask them to serve as your **advocate, extra pair of eyes and ears, and note-taker.**

No matter what you need from your buddy, make sure you are clear about it. Your doctor will want you to do most of the talking. But it's okay to ask your advocate to "butt in" if you're having trouble expressing yourself.

☐ **Step 5: Gather your medical records.** If you've been to another doctor or specialist **since your last visit** to this doctor, find copies of any appointment notes you may have received at checkout. If you've had any visits to an emergency room or urgent care center since your last visit, be sure to take copies of those records, as well.

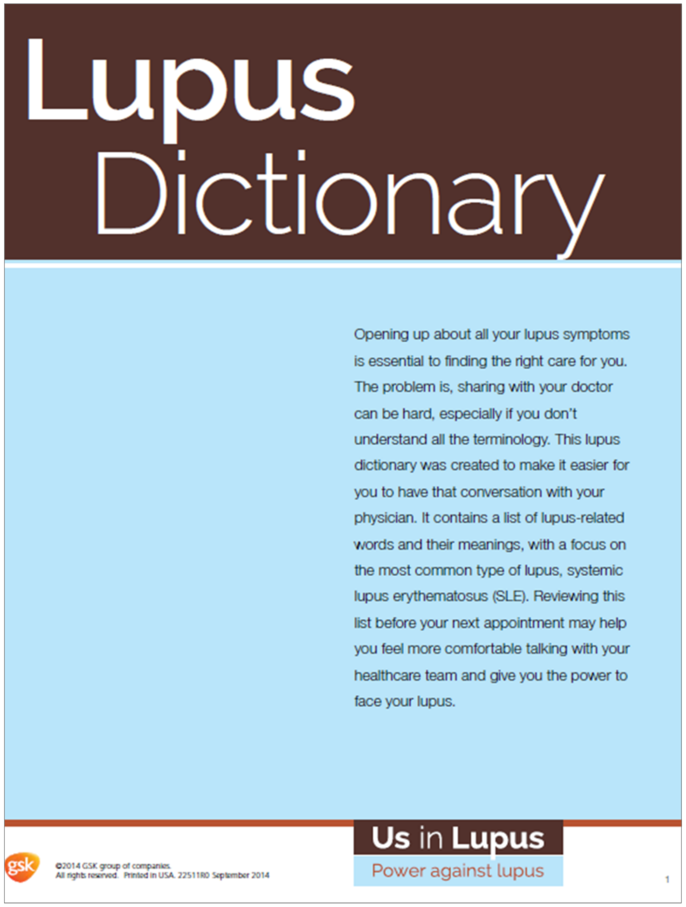
Continued on back side

Us in Lupus
Power against lupus

Lupus **Dictionary**

This free list of lupus-related terms can help you prepare for medical appointments and better understand the conversations you have with your healthcare team

✓ To download, simply visit www.usinlupus.com



Lupus Dictionary

Opening up about all your lupus symptoms is essential to finding the right care for you. The problem is, sharing with your doctor can be hard, especially if you don't understand all the terminology. This lupus dictionary was created to make it easier for you to have that conversation with your physician. It contains a list of lupus-related words and their meanings, with a focus on the most common type of lupus, systemic lupus erythematosus (SLE). Reviewing this list before your next appointment may help you feel more comfortable talking with your healthcare team and give you the power to face your lupus.

Printed in USA. 22511R0 September 2014

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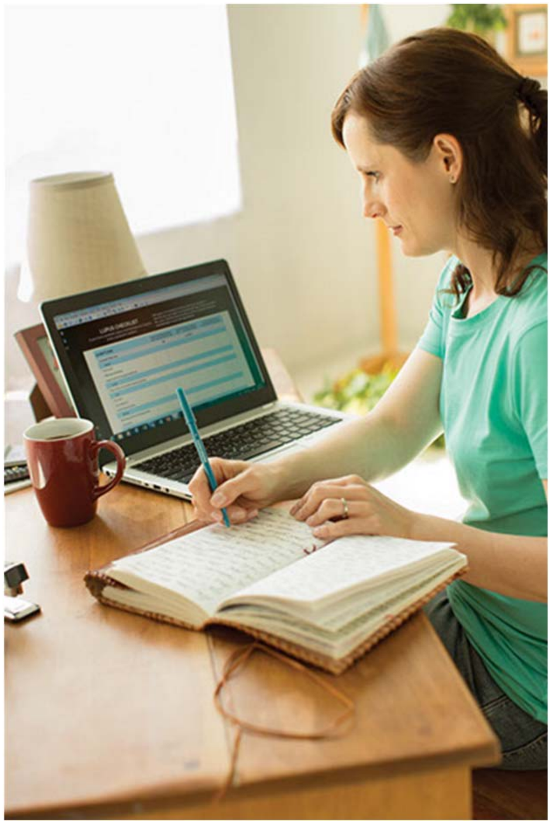
Power against lupus

Reflection: Consider Using These **Tools**

Take a moment for some self-reflection

- What are your challenges in living with lupus?
- How can these tools help?
- How can you use each of these tools?
- Pick one tool, and visualize yourself using it. Do you think you can implement it into your management plan?



Seek Patient **Support**

- Find a local advocacy group
- Reach out to lupus organizations and educational programs
- The following resources can help:

Help Us Solve
The Cruel Mystery
LUPUS™
FOUNDATION OF AMERICA

www.lupus.org

the
lupus
initiative
Eliminating Health Disparities in Lupus

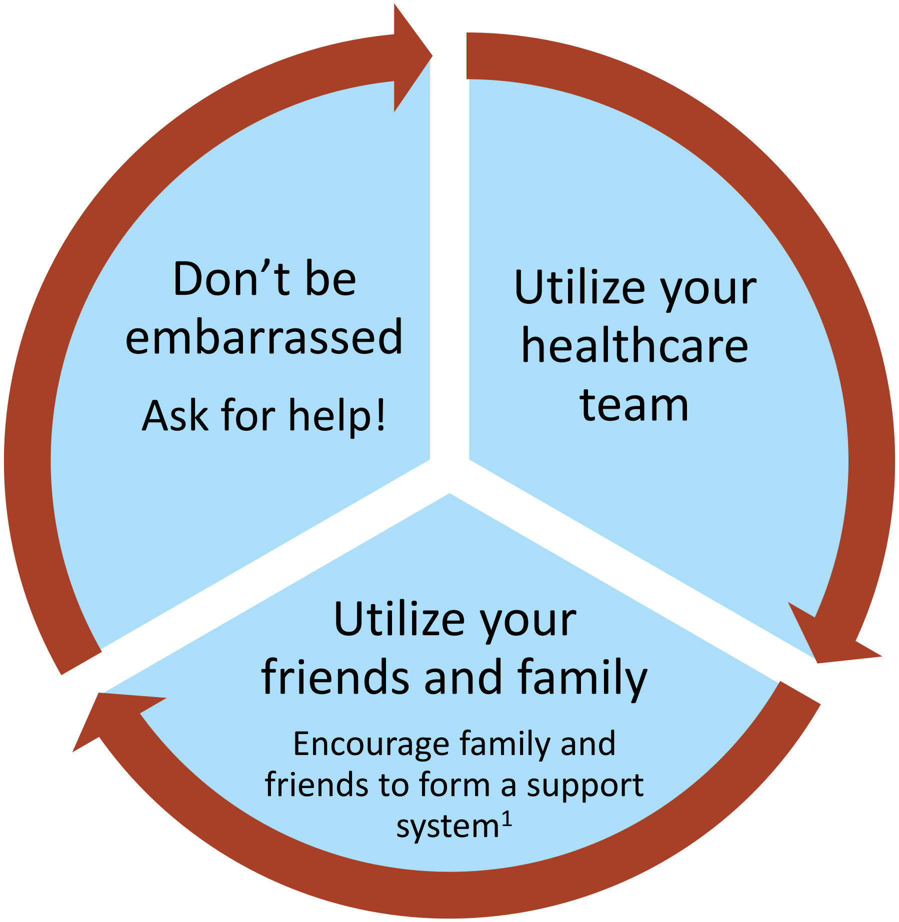
www.thelupusinitiative.org

Lupus
Research
Institute

www.lupusresearchinstitute.org

Please Note: These resources are external to GSK. GSK does not have control over the content or information provided through these resources, and accordingly does not warrant their accuracy or completeness.

You Are **Not Alone!**



Don’t be embarrassed

Ask for help!

Utilize your healthcare team

Utilize your friends and family

Encouraging family and friends to form a support system[1]

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[1] Isherwood DE. In: Carter SC, et al, eds. *Core Curriculum for Rheumatology Nursing.* 1st ed. Greenville, SC: Lyons Den Solutions, LLC; 2015:213-228.

Summary: **You** Are a **Key Component** in Assessing Your Disease Activity

- Know that **you** play an important role in managing your lupus
- Promote **open** and **honest** communication
- Take advantage of **tools** and **resources** available to you
- Stay active in being **educated** on your lupus

You Are **Empowered.** You Can Be Your Own **Advocate.**

"For those of you who are living with lupus, I encourage you to listen to your body. Learn your body, and build a strong and open relationship with your doctors. It's extremely important. Life is just way too short and precious to take it for granted."

Rena, currently living with lupus

Rena is a paid spokesperson for GSK