

LUPUS NEPHRITIS

— SELF-MANAGEMENT —



EMPOWER:

LUPUS NEPHRITIS SELF-MANAGEMENT SUPPORT GUIDE FOR CLINICAL PROFESSIONALS

AMERICAN COLLEGE
of RHEUMATOLOGY
Empowering Rheumatology Professionals



lupusinitiative.org/selfcare

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Welcome to the American College of Rheumatology's **EmPower: Lupus Nephritis Self-Management Support Guide for Clinical Professionals**

These tools were created by a panel of experts including rheumatologists, rheumatology health professionals, nephrologists, and people living with lupus nephritis.

The materials and resources included in this Guide were designed for physicians and other clinical professionals with specialties in, but not limited to, rheumatology, nephrology, primary care, obstetrics and gynecology. Currently, lupus nephritis self-management resources are limited, and many clinical healthcare professionals are uncertain where to direct patients to obtain materials on self-management.

The American College of Rheumatology (ACR) recognizes that there are numerous challenges faced by practitioners, such as limited time and staff support. This Guide was developed to help address these barriers by providing resources for practitioners to help provide self-management support in clinical settings to people living with lupus nephritis.

This Guide is designed to help you:

- Describe self-management
- Explain how self-management can help patients with lupus nephritis manage their health
- Identify the major areas of self-management and opportunities to provide self-management support in each area
- Empower your patients living with lupus nephritis to set and work toward goals in the various self-management areas

The **EmPower: Lupus Nephritis Self-Management Support Guide for Clinical Professionals** has three sections:

- **Overview:** provides an overview of the purpose of the Guide, its contents and scenarios for healthcare practitioner use.
- **Steps to success:** explains the recommended steps to optimize the self-management support that you can provide to your patients with lupus nephritis.
- **Suggested ways to use the ACR's self-management materials with patients:** provides suggestions on which resources from the **EmPowered: Self-Management Tools for People Living with Lupus Nephritis** collection may be of help to your patient, organized by topic area.

Available resources that complement this Guide

As you increase your knowledge around lupus nephritis self-management support, it may be helpful to familiarize yourself with the American College of Rheumatology's **EmPowered: Self-Management Tools for People Living with Lupus Nephritis**. These tools are handouts, videos and other resources designed to support patients and caregivers in their lupus nephritis journey. There is also a parallel version of this Guide designed specifically for clinical professionals, which we encourage you to share with members of your team. Both the program materials and the Guides can be found at lupusInitiative.org/selfcare.

Managing a chronic illness such as lupus nephritis can be a challenge and many patients feel overwhelmed. Providing self-management support may help patients take charge of their health and may also make their treatment more effective.

OVERVIEW

Self-management support is the optimal blend of information, guidance and encouragement. The **EmPower: Lupus Nephritis Self-Management Support Guide for Clinical Professionals** can help you to incorporate these elements into your clinical care. The information provided in this Guide is designed to address two likely scenarios that clinical healthcare professionals may encounter:

Scenario one: A patient is struggling with treatment plan adherence for various reasons. In this scenario, you and the patient may discuss:

- Barriers to adherence
- Appropriate actions to take
- People and resources that can aid and support

Scenario two: A patient wants to become a more active participant in their healthcare. In this scenario, you and the patient may discuss:

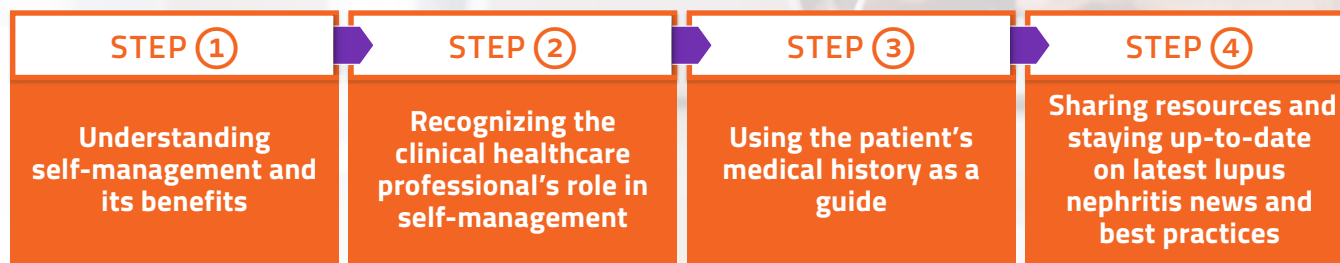
- Self-management goals
- How to track progress toward these goals
- People and resources that can support the achievement of each goal

In both scenarios, there are circumstances that affect the patient's ability to become an effective self-manager of their lupus nephritis symptoms and treatment plan. These include health status and lifestyle choices, disease knowledge and health literacy, as well as the patient's personality traits, communication skills, home or work challenges, support network, financial status and their relationship with you. These factors can influence whether the patient can implement and sustain self-management behaviors.

Although you cannot entirely address each of these factors, you can help your patients recognize and address barriers to successful self-management in each area. This is why you play a critical role in supporting patients on their self-management journey.

STEPS TO SUCCESS TO SUPPORT YOUR LUPUS NEPHRITIS PATIENTS IN SELF-MANAGEMENT

Following best practices and recommendations from rheumatologists, nephrologists, and other healthcare professionals, we have compiled four key steps to aid you in providing self-management support to your patients.



STEP ①

Understanding self-management and its benefits.

Self-management provides patients with a roadmap and tools for taking an active role in their healthcare and improving their quality of life. It can strengthen the partnership between healthcare professionals and patients and may improve outcomes.

What is self-management?

For the purpose of this Guide and other self-management related resources developed by the American College of Rheumatology, self-management is defined as a person's continuous engagement in their healthcare to understand the illness, participate in the determination of a treatment plan, understand and adhere to the treatment plan, and feel empowered to discuss ongoing symptoms and challenges with their healthcare team.

Patient and provider benefits

- Benefits to patients include:
 - » Clear guidelines for managing lupus nephritis between medical office visits
 - » Improved health outcomes
 - » Greater trust and satisfaction with healthcare provider interactions
 - » Improved health-related quality of life
- Benefits to providers include:
 - » More effective and efficient medical office visits
 - » Improved patient-provider communication and relationship
 - » Stronger patient accountability to manage lupus nephritis between medical office visits
 - » Increased patient adherence to treatment plans and recommendations

Major topic areas of self-management

Self-management spans several topic areas. Self-management aims to equip lupus nephritis patients with the knowledge and skills they need to partner with their healthcare provider to adequately treat their lupus nephritis and maintain a good quality of life. Self-management topic areas include:

1. Management of physical symptoms

To self-manage their physical symptoms, it is important for patients to be able to recognize warning signs of lupus flares or worsening kidney disease. This topic area includes encouraging patients to track and monitor symptoms and medication side effects.

2. Medication decision-making and adherence

It is important for patients to know how to work with their rheumatologist and nephrologist to choose the best medication for their lupus nephritis, and to take the medication as prescribed. This topic area includes an explanation of the importance of understanding medications, keeping track of medications, and managing medication side effects.

3. Effective communication with your healthcare provider

Communication between the healthcare provider and patient lies at the center of self-management. The patient's success in adopting self-management skills depends heavily on the level of communication and the relationship they have with their healthcare provider. It is very important that patients feel comfortable asking questions and discussing health concerns with their healthcare providers. This area includes encouraging patients to share their concerns, ask questions, and report any changes in their disease activity that they may be experiencing.

4. Lifestyle management

Healthy lifestyle habits, including family planning, reproductive health, nutrition and exercise, are important topics for lupus nephritis patients as they have implications for the progression of the condition. This area includes discussing reproductive health early and often with all patients, not just women of child-bearing age.

Self-management may seem like a big task to your patients, but you can help them divide it into smaller, more manageable tasks.

STEP ②

Recognizing the clinical healthcare professional's role in self-management.

As a clinical healthcare professional, it is important to recognize the impact you can have when you convey the value of self-management to your patients and encourage and support them to develop self-management skills. You can do this by:

- Discussing patients' self-management needs based on where they are in their treatment plan
- Identifying barriers that hinder patients in meeting their self-management goals
- Matching identified needs to self-management action items for your patients

Your role in providing self-management support is to educate patients on the benefits of self-management, encourage them to want to practice self-management, and empower them by providing support to develop skills.

The self-management team

The self-management team comprises of the patient with lupus nephritis, the team of doctors, the team of ancillary healthcare staff, and individuals who support the patient outside of the clinic setting.

This ensures that patients receive information, guidance and encouragement before, during and after medical appointments and the same messages are reinforced in different conversations. Additionally, healthcare providers can leverage medical technologies (e.g. patient portals or text message) as a complement to interpersonal interactions.

It is beneficial and necessary for self-management support to come from various sources.

Barriers that hinder self-management

Understanding the barriers to health behavior change and readiness to practice self-management helps healthcare providers know how to help their patients. For example, you might identify barriers that hinder a patient's adherence to a treatment plan or medical recommendations. Once you identify these barriers, you can determine how to best help this patient overcome them.

As you know, nonadherence can be caused by several factors including medication side effects, financial challenges, under-insurance or lack of insurance coverage, family commitments, transportation needs, as well as a patient's disease knowledge and attitudes/beliefs about treatment efficacy.

However, recognizing these barriers is just the first step. Once you have identified why your patient is not adhering to the treatment plan, you can direct them to resources to help address and overcome some of these barriers. In the next section we discuss strategies healthcare providers can implement to help patients.

Three strategies to help patients overcome barriers to self-management

1. Identify and discuss possible solutions with your patients.

Helping your patients overcome barriers to self-management can empower patients. Talking through solutions when patients are not adhering to the treatment plan can help them feel more involved and accountable in their treatment.

2. Increase effectiveness of patient conversations through open communication.

Self-management support is a unique part of clinical healthcare that needs to be intentional and pre-planned for maximum effectiveness. Self-management support does not require long conversations with your patients. Rather, it involves having effective conversations in which you encourage and assist with goal setting and refer patients to available resources. This is best accomplished when encouraging open, honest, non-judgmental communication with your patients.

3. Direct patients to resources tailored to their individual needs.

After identifying barriers, you can direct your patients toward self-management resources to help them succeed.

Helpful tips:

- Highlight barriers that hinder your patient from meeting self-management goals.
- Match identified needs to self-management action items for your patient.
- Discuss the self-management tools available based on where your patient is in their treatment plan.

STEP ③

Using the patient's medical history to determine and encourage necessary self-management skills.

Several factors determine a patient's willingness and ability to manage a chronic disease such as lupus nephritis. The greater your understanding of a patient's unique circumstances and challenges, the better able you are to provide effective self-management support.

Patient-provider communication

As a clinical healthcare provider, you know a great deal of information about your patient's lupus nephritis, including its characteristics and the patient's treatment plan.

You are also privileged to have firsthand knowledge of your patient's personality traits, family, social and work dynamics and the effect lupus has on their daily life.

This information becomes the foundation for helping your patient build self-management skills to mitigate the impacts of lupus nephritis on their life.

Effective patient and provider communication is a critical part of the patient-provider relationship. This is also an essential part of the self-management relationship. By combining health data with your knowledge about the patient, you can help determine the skills and resources that are most needed for their self-management journey.

You are uniquely qualified to provide personalized guidance and encouragement that helps patients feel confident in their ability to be effective self-managers and accomplish meaningful goals.

Determining self-management goals for your patients

Identifying the most important areas and skills for your patients allows you to establish patient-specific self-management goals. These goals may be altered as disease activity and patient needs change.

The tools listed below may help as you provide care to your lupus nephritis patients and support them in building self-management skills. Encourage your patients to create lists or logs such as:

- A list of your patient's top three questions or concerns to ask you at an upcoming visit
- A list of all medications
- A symptom journal/log
- A blood pressure journal/log



Sharing resources with patients and staying up-to-date on self-management best practices.

Sharing self-management resources with your patients

Although there are few self-management related resources specifically for people living with lupus nephritis available, you may find helpful resources that are not specific to lupus nephritis. These may include resources focusing on self-management support, chronic disease self-management, and SLE self-management.

The resources that will be most helpful will likely vary depending on your patient's specific self-management needs. How you use these materials with your patients may also vary. You may find it helpful to have resources available in print that you can review with your patients during their appointments or you may wish to have a list of resources available online that you can give to the patient as suggestions and then discuss any questions they may have about them at their next appointment.

The American College of Rheumatology has created resources to help you provide self-management support to people living with lupus nephritis. These resources are available at lupusinitiative.org/selfcare. Suggestions on how and when to use these materials are provided on the next page.

Staying up-to-date on lupus nephritis latest news

It can help to stay up-to-date on the latest lupus nephritis news, best practices and guidelines. The American College of Rheumatology's Lupus Initiative website contains self-management resources that you can use with your patients. Additional resources for providers are available in the form of practice guidelines at: www.rheumatology.org.

Discussing self-management with your colleagues

Expanding awareness of the value of providing self-management support and making tools available to peers and staff can have a positive impact on the care, health outcomes and provider satisfaction of lupus nephritis patients.

Opportunities to involve others in lupus nephritis self-management discussions include:

- Conferences
- Staff meetings/huddles
- Local lupus patient advocacy groups

Self-management provides patients with a roadmap and tools for taking an active role in their healthcare and improving their quality of life. It can strengthen the partnership between healthcare professionals and patients and may improve outcomes.



SUGGESTED WAYS TO USE ACR'S SELF-MANAGEMENT MATERIALS WITH PATIENTS

This table provides suggestions on which resources from the *EmPowered: Self-Management Tools for People Living with Lupus Nephritis* collection may be of help to your patient. These tools are organized by topic area and available at lupusinitiative.org/selfcare.

Self-Management Topic Area	Resources to Address Relevant Skills
Management of Physical Symptoms	<p>Handout</p> <ul style="list-style-type: none"> ➤ Applying Self-Management to Your Daily Life: Managing Physical Symptoms <p>Animated videos</p> <ul style="list-style-type: none"> ➤ Video 1: Lupus nephritis overview ➤ Video 2: Lupus nephritis can have lasting effects ➤ Video 3: What is self-management and why is it important? ➤ Video 6: Self-management Skill Builder: Understanding your lab tests <p>Patient/provider video</p> <ul style="list-style-type: none"> ➤ Self-management advice from doctors who treat lupus nephritis
Medication Decision Making and Adherence	<p>Handout</p> <ul style="list-style-type: none"> ➤ Applying Self-Management to Your Daily Life: Medication Decision Making <p>Animated videos</p> <ul style="list-style-type: none"> ➤ Video 5: Self-management Skill Builder: Managing your medications ➤ Video 6: Self-management Skill Builder: Understanding your lab tests <p>Patient/provider video</p> <ul style="list-style-type: none"> ➤ A word from doctors who treat lupus nephritis
Effective Communication with Healthcare Providers	<p>Handouts</p> <ul style="list-style-type: none"> ➤ Applying Self-Management to Your Daily Life: Communicating with Your Healthcare Team ➤ Applying Self-Management to Your Daily Life: Practicing Self-Management with Your Healthcare Team <p>Animated videos</p> <ul style="list-style-type: none"> ➤ Video 4: Self-management Skill Builder: Communicating with your healthcare team <p>Patient/provider videos</p> <ul style="list-style-type: none"> ➤ A word from doctors who treat lupus nephritis ➤ The lupus nephritis self-management team
Lifestyle Management	<p>Handout</p> <ul style="list-style-type: none"> ➤ Applying Self-Management to Your Daily Life: Lifestyle Management <p>Animated videos</p> <ul style="list-style-type: none"> ➤ Video 7: Adopting a healthy lifestyle ➤ Video 8: Healthy living tips <p>Patient/provider videos</p> <ul style="list-style-type: none"> ➤ People living with lupus nephritis talk about their journey with the disease ➤ People living with lupus nephritis explain what self-management means to them ➤ People living with lupus nephritis explain how they practice self-management ➤ Self-management advice from people living with lupus nephritis ➤ Advice for someone who is newly diagnosed with lupus nephritis

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