



LUPUS NEPHRITIS

— SELF-MANAGEMENT —

EMPOWER:

LUPUS NEPHRITIS SELF-MANAGEMENT SUPPORT GUIDE FOR NON-CLINICAL PROFESSIONALS

AMERICAN COLLEGE
of RHEUMATOLOGY
Empowering Rheumatology Professionals



lupusinitiative.org/selfcare

LUPUS NEPHRITIS

—SELF-MANAGEMENT—

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TABLE OF CONTENTS

4	WELCOME
5	OVERVIEW
6	STEPS TO SUCCESS TO SUPPORT YOUR LUPUS NEPHRITIS PATIENTS IN SELF-MANAGEMENT
6	STEP 1: Understanding self-management and its benefits
	What is self-management?
	Benefits for people living with lupus nephritis
	Major topic areas of self-management
7	STEP 2: Recognizing your role in self-management support
	The self-management team
	Barriers that hinder self-management
	Strategies to support self-management skill-building
9	STEP 3: Using your patient's experiences to encourage self-management skill development
	Understanding your patient's lupus nephritis journey
	Assessing the impact of lupus nephritis on your patient's life
10	STEP 4: Sharing resources and staying up-to-date on latest lupus nephritis news and best practices
	Discussing self-management with non-clinical professionals
	Sharing self-management resources with your patients
11	SUGGESTED WAYS TO USE ACR'S SELF-MANAGEMENT MATERIALS WITH PATIENTS

Welcome to the American College of Rheumatology's **EmPower: Lupus Nephritis Self-Management Support Guide for Non-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 individuals who support people living with lupus nephritis and includes, but is not limited to, patient advocates/navigators, community health workers, support group leaders, health coaches, peer mentors, and clinical office support staff and administrators. Currently, lupus nephritis self-management resources are limited and individuals who support patients* are uncertain where to direct them to obtain materials on self-management.

The American College of Rheumatology (ACR) recognizes that there is a need for support outside of the clinic setting. This Guide was developed to help non-clinical professionals provide self-management support 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 patients to set and work towards goals in the various self-management areas

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

- **Overview:** provides an overview of the purpose of the Guide, its contents, and scenarios for when to use.
- **Steps to success:** explains the recommended steps to optimize the self-management support that you can provide to people living with lupus nephritis.
- **EmPowered: Self-Management Tools for People Living with Lupus Nephritis:** provides suggestions on which resources from the **EmPowered: Self-Management Tools for People Living with Lupus Nephritis** may be of help to your patients.

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.

*Throughout this Guide, we will refer to the people living with lupus nephritis to whom you provide support as "patients"

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 Non-Clinical Professionals** can help you to incorporate these elements into the care and support you provide to your patients. The information provided in this Guide is designed to address two likely scenarios that non-clinical professionals may encounter:

Scenario one: A patient on your caseload is having difficulty keeping up with the treatment plan given to them by their rheumatologist or nephrologist. The patient may likely have issues in their life that are preventing them from adequately managing their condition. In this scenario, the two of you may discuss:

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

Scenario two: A member of your support group or your mentee expresses their desire to become a more active participant in their healthcare. In this scenario, the two of you 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 person'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 person's personality traits, communication skills, home or work challenges, support network, financial status and their relationship with you. All of these factors can influence whether the person 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 people with lupus nephritis on their self-management journey.

STEPS TO SUCCESSFULLY SUPPORT PEOPLE LIVING WITH LUPUS NEPHRITIS IN SELF-MANAGEMENT

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



STEP ①

Understanding self-management and its benefits.

Self-management provides people living with lupus nephritis 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 lupus nephritis patients and their healthcare team 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 decision of a treatment plan, understand and adhere to the treatment plan, and feel empowered to discuss ongoing symptoms and challenges with their healthcare team.

Benefits of self-management

- Greater trust and satisfaction with healthcare provider interactions
- Improved health-related quality of life and health outcomes

Major topic areas of self-management

Self-management spans several topic areas. Self-management aims to equip people living with lupus nephritis with the knowledge and skills they need to partner with their healthcare team 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 people living with lupus nephritis 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

It is important for people living with lupus nephritis 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 not only encouraging patients to share their concerns, but also to ask questions and report any changes in their disease activity that they may be experiencing.

4. Lifestyle management

Healthy lifestyle choices including careful family planning, reproductive health, nutrition, and exercise, are important for people living with lupus nephritis as these choices have implications for the progression of their 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 your role in self-management support.

As an individual supporting patients in self-management outside of the clinic setting, you are someone who will encourage patients to set goals and apply self-management skills in their lives. You can do this by:

- Discussing your patient's self-management needs according to their treatment plan
- Identifying barriers that hinder your patient in achieving their self-management goals
- Matching identified needs to self-management actions for your patients

The self-management team

The self-management team consists 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.

A team approach ensures that patients receive information, guidance, and encouragement before, during, and after medical appointments and the same messages are reinforced in different conversations.

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

Barriers that hinder self-management

It is important that you understand barriers to adopting self-management skills so you can know how to help your patient overcome them. For example, you might identify specific barriers that hinder your patient's ability to take their medications as prescribed. Once you identify these barriers, you can determine how to best help your patient overcome them.

As you know, when a patient is having trouble following their treatment plan it may be due to one or a combination of factors, such as side effects, finances, insurance coverage, family responsibilities, transportation needs, and even the patient's disease knowledge and attitudes or beliefs about how well their treatment is working.

However, recognizing these barriers is just the first step. Once you have identified why a patient isn't following their treatment plan, you can direct them to resources to help overcome some of these barriers. In the next section, we discuss strategies that individuals supporting people living with lupus nephritis can implement to help.

Strategies to support self-management skill-building

1. Identify and discuss possible solutions.

Helping patients overcome barriers to self-management can empower them. Talking through solutions when patients are having trouble following their treatment plan can help them feel more involved in their treatment.

2. Establish open communication.

You have the unique opportunity to get to know your patient on a personal level outside of the clinic setting. It is important to have open and honest communication during conversations since the information you gather will help you provide effective encouragement and guidance.

3. Direct patients to resources unique to their needs.

After identifying barriers and specific needs, you can direct patients toward self-management resources to help them succeed. The ACR developed a collection of resources, ***EmPowered: Self-Management Tools for People Living with Lupus Nephritis***, which is available at lupusinitiative.org/selfcare.

Helpful tips to go along with these strategies:

- Highlight barriers that hinder your patients from meeting self-management goals.
- Match their identified needs to self-management action items.
- Discuss the self-management tools available according to each patient's unique situation.

STEP ③

Using your patient's experiences with lupus nephritis to enhance self-management skills.

Doctors often have limited time with patients during medical office visits. Outside of the clinic, people living with lupus nephritis may have the option to discuss their experiences in detail and at length. With this advantage, you have the opportunity to gather a great deal of information and use that information to encourage self-management skill-building with your patients.

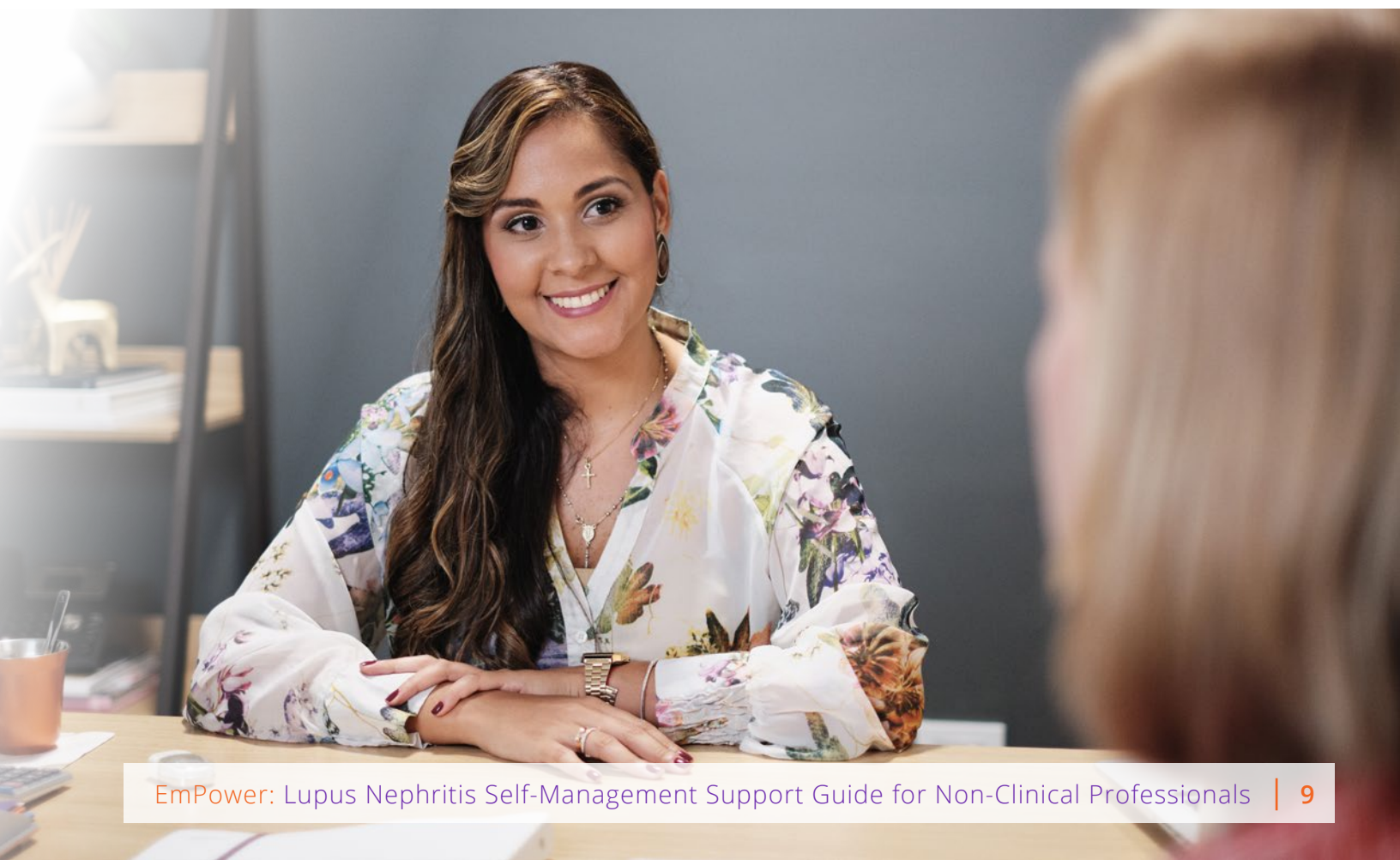
Understanding your patient's lupus nephritis journey

It is important to gather information about the specific challenges that your patient faces, such as their history with the disease, characteristics of their disease, common symptoms, and their current treatment plan. Understanding their journey will also assist in understanding barriers to self-management that they may be experiencing.

Assessing the impact of lupus nephritis on your patient's life and help to address specific challenges

Using information from your patient's past and more up-to-date information, you can assess how lupus nephritis has impacted your patient's life. This assessment will help inform you of the self-management areas on which your patient needs to focus.

The table found at the end of this Guide provides a listing of the ACR's self-management resources matched to various self-management topic areas. You can use this table to find resources to address your patient's specific challenges.



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

Sharing self-management resources with your patients

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

The relevance and value of those resources depend on the specific self-management needs of your patient. How you use these materials with your patient may also vary. You may find it helpful to have printed resources that you can review with your patient when you meet with them. You may also wish to have a list of resources available online that you can give as suggestions and then discuss any questions they may have about them the next time you meet.

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 the latest news in lupus nephritis

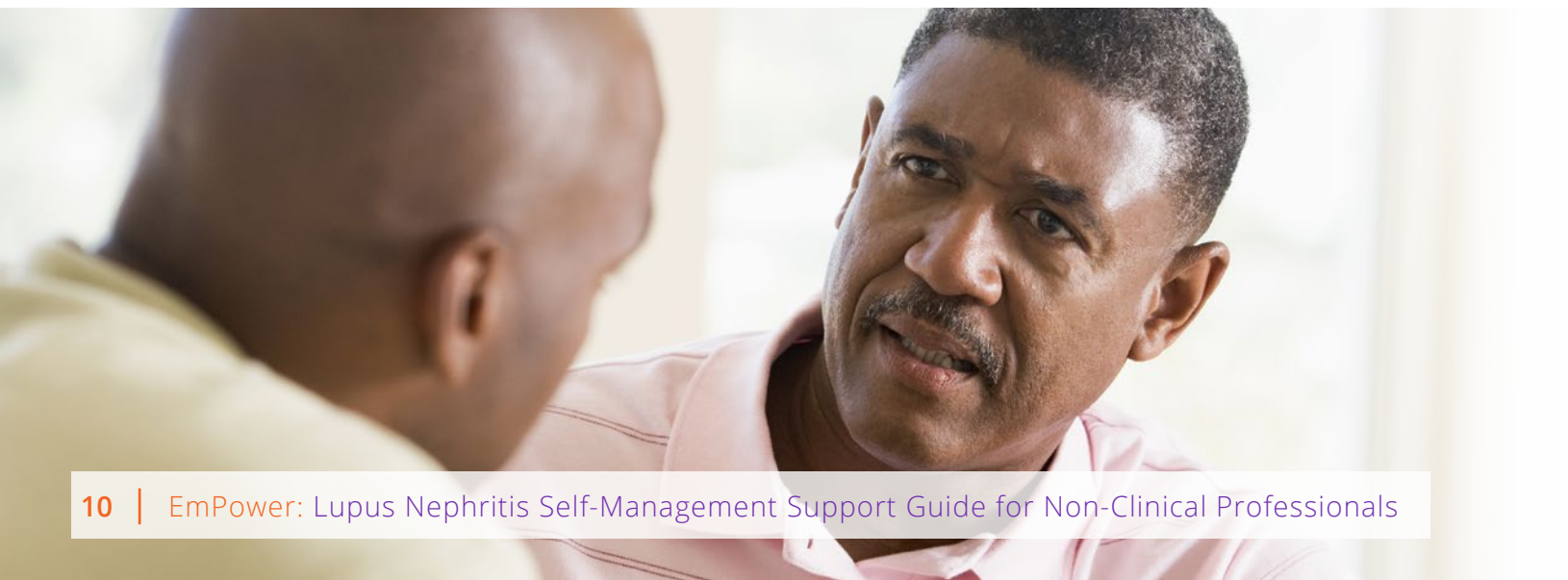
It can help to stay up-to-date on the latest news in lupus nephritis and Guidelines for care. The American College of Rheumatology's Lupus Initiative website contains self-management resources that you can use with your patients.

Discussing self-management with other individuals providing self-management support outside of the clinic

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 and health outcomes of people with lupus nephritis.

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

- Social media (Facebook, Twitter, Instagram)
- Lupus support groups
- Local lupus advocacy events
- Local health fairs or conferences



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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