



LUPUS NEPHRITIS

— SELF-MANAGEMENT —

EMPOWERED: SELF-MANAGEMENT TOOLS FOR PEOPLE LIVING WITH LUPUS NEPHRITIS

AMERICAN COLLEGE
of RHEUMATOLOGY
Empowering Rheumatology Professionals



lupusinitiative.org/selfcare



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WHAT IS SELF-MANAGEMENT AND HOW CAN IT HELP PEOPLE LIVING WITH LUPUS NEPHRITIS?

EMPOWERED:
SELF-MANAGEMENT TOOLS
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What is self-management?

The American College of Rheumatology (ACR) defines self-management 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.

Disease knowledge and individual needs

The first step to becoming an active self-manager of lupus nephritis is to learn all you can about the disease. See the Lupus nephritis overview at lupusinitiative.org/selfcare which provides an overview of lupus nephritis along with the signs and symptoms.

Lupus nephritis affects everyone differently. Each person has different strengths and obstacles that can affect how they manage the disease. So, it is important to understand the skills and support you need to successfully manage lupus nephritis and your overall health.

In these handouts, you will gain information and learn skills related to self-management. Each area discussed is important, but it is okay to focus on one area before taking on a new one. Each handout will help you partner with your healthcare team to manage your health.

Self-management skills can improve three areas of your health

 **physical**

 **mental**

 **emotional**

The handouts listed below are available to help you gain information and learn skills in four areas of self-management.

APPLYING SELF-MANAGEMENT TO YOUR DAILY LIFE
MANAGING PHYSICAL SYMPTOMS

Managing your physical symptoms

Self-management goal setting for physical symptoms

PHYSICAL SYMPTOMS

APPLYING SELF-MANAGEMENT TO YOUR DAILY LIFE
MEDICATION DECISION MAKING

Medication decision-making

Understanding your medications

Keeping track of your medications

Managing medication side effects

MEDICATION DECISION MAKING

APPLYING SELF-MANAGEMENT TO YOUR DAILY LIFE
COMMUNICATING WITH YOUR HEALTHCARE TEAM

Communicating with your healthcare team

Making the most of your appointments

COMMUNICATING WITH YOUR HEALTHCARE TEAM

APPLYING SELF-MANAGEMENT TO YOUR DAILY LIFE
LIFESTYLE MANAGEMENT

Lifestyle management and family planning

Lifestyle Management

For additional information and resources visit lupusinitiative.org/selfcare

APPLYING SELF-MANAGEMENT TO YOUR DAILY LIFE

MANAGING PHYSICAL SYMPTOMS

SELF-MANAGEMENT TOOLS
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Managing your physical symptoms

To better manage your physical symptoms, it is important to recognize warning signs of lupus flares or worsening kidney disease. Lupus and lupus nephritis are often referred to as “invisible illnesses” because the signs and symptoms are not always visible to the eye. There are times when some people with lupus nephritis may not feel sick. Others may get used to not feeling well and think they should just “carry on” with life. Allowing the disease to worsen will make it harder to reverse the inflammation and damage happening in your kidneys, take care of your family, go to work, and participate in other activities that are important to you.

Even if you do not feel sick, you should follow your rheumatologist and/or nephrologist’s directions, which includes:

- ➔ Taking your medications as prescribed.
- ➔ Attending scheduled appointments to monitor your kidneys.
- ➔ Practicing healthy lifestyle habits that may help your disease.



Lupus nephritis may cause subtle symptoms or even no symptoms in the early stages. If one or more of the following symptoms occur, contact your healthcare provider as soon as possible to discuss them.

- ➔ Swelling in the feet, ankles, legs, or around your eyes.
- ➔ Bloody or foamy urine.
- ➔ Needing to urinate more often than usual, especially at night.

You know your body the best. That is why you are an equal partner with your healthcare team in monitoring your symptoms. If anything seems different, let your doctor know as soon as possible.

Self-management goal setting for physical symptoms

To help you set goals for managing your physical symptoms, it is recommended that you keep a journal or log to:

1. Track new symptoms and when they started.
2. Track existing symptoms that are improving.
3. Track existing symptoms that are not improving or getting worse.
4. Track your blood pressure if your healthcare team believes that blood pressure management is a good self-management skill for you to have.



If you miss tracking your symptoms one day, don’t be too hard on yourself. Once you remember, add the tracking information to your journal or log.

Use a journal or log to monitor your symptoms. Take your symptom tracking information to all healthcare provider appointments. Life can get very busy but try and make these actions a regular habit.

Adding a reminder to a daily calendar may help.

Some lifestyle changes can lessen some physical symptoms of lupus nephritis. See the *Lifestyle Management* handout for more information at lupusinitiative.org/selfcare.

APPLYING SELF-MANAGEMENT TO YOUR DAILY LIFE

MEDICATION DECISION MAKING

SELF-MANAGEMENT TOOLS
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Medication decision-making

The *Communicating with your healthcare team* video found at lupusinitiative.org/selfcare explains why working with your doctors to choose the best medication, and taking it correctly, is an important part of lupus nephritis self-management.

Medication decision-making relates to the partnership between a patient and a physician to determine the best medication to prescribe for lupus nephritis.

Understanding your medications

You are more likely to take your medication if you understand:

- ➔ Why was this medication chosen?
- ➔ How does this medication help my lupus nephritis?
- ➔ How will I know that the medication is working?
- ➔ What are the side effects that I should expect?
- ➔ What should I do about the side effects?



You should feel confident asking your healthcare providers or pharmacist these questions.

Keeping track of your medications

Bring a list of your medications to all of your medical appointments and pharmacist visits.

It is critical that your healthcare providers and pharmacist have this information so they can protect you from harmful drug interactions that may:

- ➔ Prevent your lupus nephritis medications from working.
- ➔ Make medication side effects worse.
- ➔ Cause damage to your kidneys and other organs.

Your rheumatologist or nephrologist should know about any medications that were prescribed by another healthcare provider as well as any supplements, vitamins, or over-the-counter medications that you are taking.

Managing medication side effects

Medication side effects can be difficult to deal with. However, it is important to know that it can be dangerous to stop taking your lupus medications. Tell your healthcare providers about any side effects you are experiencing. Together, you can determine if you:

- ➔ Are confusing a lupus nephritis symptom with a drug side effect.
- ➔ Can change the dosage of your medication and how that may lessen side effects.
- ➔ Should try a new medication and what side effects to expect.

It is a good idea to keep track of medication side effects in the same way you track your physical symptoms. That way, you will have all the information you need to discuss with your healthcare team in one place.

Alert your healthcare provider about the symptoms that you are experiencing, and work with them to make any changes to your medications. Do not stop taking your medication suddenly unless directed by your doctor.

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Self-management goal setting for medication decision-making

Here are goals to help manage medications that you can set and work toward:

- ➔ Make a list of all of the medications, over-the-counter drugs, and supplements that you are taking.
- ➔ Bring a list of questions about your medication, including side effects you should expect or may be experiencing to all medical appointments and pharmacist visits.
- ➔ Bring a list of refills you need with you to each medical visit to avoid running out of your medications between visits.
- ➔ Discuss any medication cost challenges you have with your healthcare provider.
- ➔ Use a day-of-the-week pill box to help you take your medications as prescribed or an app to remind you of your medication schedule. See the *Managing Medications* video at lupusinitiative.org/selfcare to learn more.
- ➔ Avoid the use of nonsteroidal anti-inflammatory drugs (NSAIDs) as they can reduce kidney function. These popular pain relievers can be easily purchased at a grocery store, pharmacy or online. These drugs include ibuprofen and naproxen sodium. Always remember that NSAIDs are included in many over-the-counter medicines for cold, allergy, sleep problems, and in headache powders.



Your medications play a central role in managing lupus nephritis. If you feel uncertain about getting started on these goals, ask for help starting with your doctors and pharmacist.

Communicating with your healthcare team

Video interviews with doctors who treat people with lupus nephritis are available at lupusinitiative.org/selfcare. In these videos, a rheumatologist and nephrologist discuss the benefits of an open and honest relationship with your healthcare providers. You will see why and how good communication can make you a better self-manager of lupus nephritis.

Explaining what you are feeling and experiencing in a clear and effective way with your doctor and healthcare team can improve your care. Your healthcare team may include a rheumatologist, nephrologist, along with a nurse practitioner and/or physician assistant. Giving detailed information to your healthcare team will help you work together to answer important questions about your disease, such as:

Your healthcare providers are important members of your self-management team!

- ➔ Is your medication working?
 - » You may want to use your physical symptoms tracking journal or log (see the *Managing physical symptoms* handout) and your list of medications (see the *Medication decision-making* handout) when talking to your provider.
- ➔ What challenges do you face that are affecting how and when you take your medication?
- ➔ Do you understand the warning signs that your disease may be getting worse?
- ➔ Do you have lifestyle habits that may worsen your disease?



Making the most out of your appointments

Proper planning will help you get the most out of each healthcare provider appointment. There is a lot of information to cover in each appointment. There may be times that you feel rushed or that you feel your concerns are being dismissed. Your healthcare team wants what is best for you and your health. However, the topics that your healthcare provider wants to focus on may not always be the same as yours. For example, maybe the discussion is focused on medication and lab results, but you are having a really difficult time with fatigue, headaches, stress, or swelling in your feet.

That is why you play a central role in helping your healthcare provider focus on your health as a whole. No topic is off-limits to discuss with your healthcare provider and it may be helpful to speak up at the beginning of the appointment.

Explaining your thoughts and feelings in an open and honest way helps your doctor partner with you to develop the best treatment plan for you.

The following are some important topics to discuss:

- ➔ New or worsening symptoms.
- ➔ Medication issues (e.g. following dosage instructions, dealing with side effects, managing multiple medications, using over-the-counter pain medicines safely).
- ➔ Insurance coverage and prescription costs.
- ➔ Daily living challenges (e.g. stress, fatigue, and nutrition).

When your doctor enters the room for your appointment, you can say, "I want to make sure that we talk about (your number one area of concern) today."

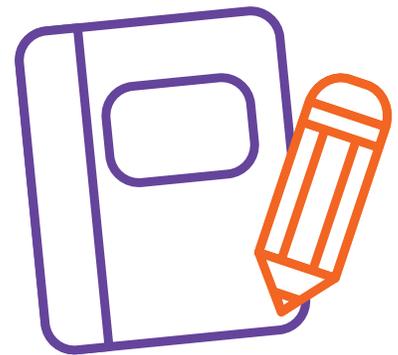
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You may be concerned that your healthcare team will judge you or your lifestyle decisions if you are honest and open. But that is not the case. Your healthcare team treats people living with lupus nephritis from all walks of life and they understand the challenges you may face. If your doctor does not fully understand what is going on with you, they cannot work with you to find the best way to manage your lupus nephritis. The more information your doctors have, the better able they are to help you.

Self-management goal setting for communicating with your healthcare team

Here are three goals related to managing communication with your healthcare provider you can set and work toward:

- ➔ Use your journal or log to monitor symptoms (see the *Managing Physical Symptoms* handout at lupusinitiative.org/selfcare) to write down any medication side effects you experience and bring it to all appointments.
- ➔ Write down one or two main issues that you want to discuss during your visit.
- ➔ Prepare a short and specific statement or question for your provider that describes what is most concerning to you. For example:
 - » I know many things affect my disease, but what's the one thing that I could start doing differently today?
 - » I feel overwhelmed by my disease and no one understands when I try to explain what I am feeling. What can I do about it?
 - » I'm taking my medication, but I have a lot of fatigue. How do I deal with that?
 - » How do I know if my medication is working?
 - » I'm having a hard time cutting salt from my diet. Is there anyone who can help me learn how to make better food choices?
 - » I would like to start or grow my family, but I am worried about how to go about doing that.



APPLYING SELF-MANAGEMENT TO YOUR DAILY LIFE

LIFESTYLE MANAGEMENT

SELF-MANAGEMENT TOOLS
FOR PEOPLE LIVING WITH
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Lifestyle management and family planning

When you are living with lupus nephritis, healthy lifestyle choices have a big impact on how well you manage your disease. People may have jobs and financial responsibilities to manage, children or family members to take care of, personal relationships and social obligations to cope with, or other life matters that can cause high levels of stress.

It is often difficult to deal with life matters and a chronic disease such as lupus nephritis.

Family planning and reproductive health

Lupus nephritis can negatively affect a person's reproductive health. Reproductive health may include safe contraception use, fertility issues, or safe medication use during pregnancy or breastfeeding. This shows the need to discuss reproductive health with your doctor.

We often discuss female reproductive health when discussing lupus nephritis, but the challenges can affect men, too. Some medications used to treat lupus nephritis may affect fertility (the ability to conceive a baby), can cause significant birth defects, and can affect the health of the mother and baby during pregnancy.

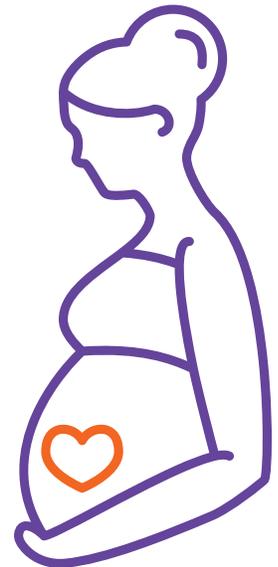
Safety is first and foremost

Before you start planning to have a child, you should talk to your doctor about reproductive health.

They can advise you about:

- ➔ The best time to start planning a family.
- ➔ Actions you should take before trying to conceive a baby.
- ➔ The ways that lupus nephritis and birth control medications can affect your reproductive health.
- ➔ How lupus nephritis can affect the health of mother and baby during pregnancy.
- ➔ The effect pregnancy can have on lupus nephritis.

Lupus nephritis is commonly diagnosed in women of child-bearing age (15-44). So, it is common for a life-changing diagnosis to occur when a woman is deciding if it is time to have her first child or have more children. Having lupus nephritis does not mean you will be unable to have children, but it does mean that pregnancy requires careful planning. Talking to your doctor can increase the likelihood of having a healthy pregnancy. Precise timing of pregnancy and selection of medication is critical and using your self-management skills can be helpful. Handouts such as *Communicating with your healthcare team* at lupusinitiative.org/selfcare provide tips that can help you have this discussion with your doctor.



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Self-management goal setting for lifestyle management

Here are five goals for lifestyle management you can set and work toward:

- ➔ Make healthy food choices.
 - » Eating healthy foods and decreasing salt/sodium intake can reduce some physical symptoms of lupus nephritis and help to protect your kidneys.
- ➔ Do what you can to reduce stress.
 - » Take time to find ways to relax. It can be as simple as talking a walk, listening to music, playing a game or doing an activity that makes you laugh. Relaxation techniques such as meditation, deep breathing and guided imagery can help.
- ➔ Promote emotional and social wellness.
 - » Building healthy relationships and practicing emotional self-care improves mental and emotional wellbeing. People who have a chronic disease such as lupus nephritis may feel isolated from friends and family who do not deal with the day-to-day experiences of a chronic illness. Finding a support group can help. It is important to have a loving support system of people who will listen to you when you need to talk, encourage you when you are feeling down, or give you useful advice because they also deal with challenges that are similar to yours.
- ➔ Look for opportunities to be active.
 - » Getting regular exercise is good for the mind and the body. It promotes better physical health, improves thinking, and helps to reduce stress. While many types of exercise are beneficial, taking walks, swimming, yoga, and tai chi are options that work well.
- ➔ Avoid smoking.
 - » Smoking harms the body and can worsen lupus nephritis in many ways. You may need to get professional help if it is hard for you to quit on your own.

Some days may be more difficult than others when working toward your lifestyle management goals. But even small steps can make a big difference.



APPLYING SELF-MANAGEMENT TO YOUR DAILY LIFE

PRACTICING SELF-MANAGEMENT WITH YOUR HEALTHCARE TEAM

SELF-MANAGEMENT TOOLS FOR PEOPLE LIVING WITH LUPUS NEPHRITIS

Self-management is a team effort

Your healthcare team may include a rheumatologist, nephrologist, along with a nurse practitioner and/or physician assistant. You and your healthcare team have the same goal: helping you live a healthy and fulfilling life as you manage lupus nephritis.

Nobody knows your body as well as you do – not even your doctors. So, it is important to describe your symptoms and concerns as best as you can to your doctors. Sharing this information at every appointment means being a strong self-advocate and an active participant in your own healthcare!

Overall, the old adage is true: communication is key. See the [Communicating with your healthcare team](#) handout for more information about communication.

When to contact your doctor for self-management help

Knowing the difference between the symptoms that can be improved with self-management and those that need to be treated by your doctor is an important self-management

If any of these symptoms occur, contact your doctor's office as soon as possible. It could mean that your treatment needs to be changed. You should ask your healthcare team which of these symptoms should be considered an emergency.

Symptoms that you should discuss with your healthcare team include:

- ➔ Swelling of your face, legs, or entire body
- ➔ Frequent urination
- ➔ Nausea
- ➔ Difficult emotions, such as feelings of isolation, hopelessness and sadness
- ➔ Decreased appetite
- ➔ Rashes
- ➔ Bloody or foamy urine or any other changes in the look of your urine
- ➔ Fever
- ➔ High blood pressure
- ➔ Worsening joint pain



Symptoms that may improve with self-management:

- ➔ Fatigue
- ➔ Feelings of anxiety
- ➔ Trouble sleeping
- ➔ High blood pressure
- ➔ Widespread muscle and joint tenderness or feeling sore all over
- ➔ Weight gain due to lifestyle (nutrition and physical activity)
- ➔ Chronic pain
- ➔ Stress

When in doubt, talk to your healthcare team.

Many of these symptoms can result from the stress of having lupus nephritis. Experiencing these symptoms does not necessarily mean that your lupus nephritis is active or that treatment needs to be changed. But you should discuss these symptoms with your healthcare team to find solutions to help you manage your disease.

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