



Questions to Ask Your Doctor About Lupus Nephritis

Whether you have recently been diagnosed with lupus nephritis (LN) or are at risk for developing the disease, you may be feeling overwhelmed, uncertain, or confused.

Routine doctor visits and starting the discussion early is a great opportunity to have informative conversations about LN and get the most out of your time. To make things a little easier at your next appointment, download or print this guide to ensure you're asking the right questions.

Where are you in your journey?

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A portrait of Nicole M., RN, a woman with long brown hair, smiling, wearing a teal patterned top.

Nicole M., RN
Nurse Case Manager

Newly Diagnosed with Lupus Nephritis

If you've recently been diagnosed with lupus nephritis, you may be feeling overwhelmed, uncertain, or confused. The following questions may help you work with your doctor to know what to expect and how best to manage your condition.

Questions to Ask Your Doctor

What does my diagnosis mean?

- ☐ Is there a way to tell how severe my lupus nephritis will become?
- ☐ Are my kidneys already damaged? If so, what is the extent of the damage?
- ☐ How will my kidney function be measured?

What can I expect in the coming months and years?

- ☐ Can you predict how my lupus nephritis diagnosis will impact me?
- ☐ What challenges, symptoms, or complications can I expect?
 - How can I better prepare for them?
 - Is there anything I can do to minimize them?
- ☐ What tests should I expect to take in the future?
- ☐ How often should I get checkups, blood work, urine tests or lab tests?

What if I'm a woman of child bearing age?

- ☐ Will I be able to get pregnant?
- ☐ What happens if I get pregnant?
- ☐ Would my treatment need to change if I become pregnant?

How can I best manage my lupus nephritis?

- ☐ What are my treatment options?
- ☐ What are the benefits and risks of each option?
- ☐ How do you decide what treatment to prescribe?
- ☐ What happens if a certain treatment doesn't work?
- ☐ Are there any other specialists I should be seeing?
- ☐ How will you interact with other doctors/specialists who treat me? How often?
- ☐ How might lupus nephritis affect my lifestyle?
- ☐ Should I make any changes to my lifestyle or diet?
- ☐ What more can I do to manage my lupus nephritis other than taking my medications as directed?

Bring These with You to Every Appointment



A list of all prescription and over-the-counter medications you are taking and their dosages (including any vitamins and/or supplements).



A copy of your medical records and any recent results from blood work and/or lab tests.



An appointment buddy—someone who can ask your doctor questions and help take notes for you.



A list of your symptoms tracked over time.

Established Lupus Nephritis

As someone living with lupus nephritis, you understand the many challenges that come with managing your disease. As you move further along in your journey, you may develop new symptoms, experience changes in your daily routine, or require additional testing. Consider the following questions to help you manage your lupus nephritis over the long term with your doctor.

Questions to Ask Your Doctor

What do my signs and symptoms mean?

- ☐ What do changes in my symptoms mean?
- ☐ Could a condition other than lupus nephritis or lupus be causing any of my symptoms?
- ☐ Could a medication I'm taking be causing these symptoms?

How will lupus nephritis impact my daily routine?

- ☐ Are there any lifestyle changes I should make?
- ☐ Are there certain foods I should stick to or try to avoid?

What if I'm a woman of child bearing age?

- ☐ Will I be able to get pregnant?
- ☐ What happens if I get pregnant?
- ☐ Would my treatment need to change if I become pregnant?

How is my treatment going?

- ☐ Do I need to add or remove a medication?
- ☐ Do I need to adjust the dose of a medication?
- ☐ Are there any vitamins, supplements, or over-the-counter medications I should or should not be taking?

Why is another treatment being added?

- ☐ What are the benefits and risks of this medication?
- ☐ Are there any possible side effects of this medication?
- ☐ How and when do I take this medication?

What else can I do to manage my lupus nephritis?

- ☐ Has my prognosis changed at all?
- ☐ Have you been interacting with the other doctors or specialists who treat me?
- ☐ What tests might I expect to take in the future?
- ☐ What will the results of these tests tell me?
- ☐ What more can I do to manage my lupus nephritis other than taking my medications as directed?
- ☐ What else do you need from me so I can help you better manage my lupus nephritis?
- ☐ Are there any clinical trials I should consider?

Remember to discuss the following with your doctor

- Any symptoms experienced since your last appointment
- The severity of each symptom (using a 1 to 10 scale)
- Any changes in your symptoms
- Your experience—positive and negative—with current medications
- How you're feeling physically and emotionally
- Any changes in your day-to-day lifestyle or routine

Established Lupus Nephritis



To ensure you get the most out of your doctor visits, keep track of your symptoms over time. This will make it easier to communicate with your doctor about how you are feeling.

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An appointment buddy—someone who can ask your doctor questions and help take notes for you.



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It is so important to advocate for yourself with your healthcare providers. Only you can fully explain all the things going on in your body. Self-advocating makes it possible to bring all concerns to the healthcare team in order for them to be addressed. In turn, this empowers you and leads to a fully aware healthcare team.

- Nicole M., Nurse Case Manager



Preparing for Your Doctor's Appointment

Whether you're meeting in person or online, here are some tips for working with your doctors:

- ☐ Keep track of your medical appointments and hospital visits
- ☐ Write down your symptoms as you experience them over time
- ☐ Organize any recent results from lab tests
- ☐ Bring an updated list of all your medications, including vitamins and supplements—even if they feel unrelated, it's important to share everything you're taking with your doctor
- ☐ Have questions ready for your doctor
- ☐ Wear loose-fitting clothing in case you need to show your doctor any visible symptoms
- ☐ Take a friend or family member with you to your appointment for moral support

If you're preparing for a telehealth appointment, you can also:

- ☐ Ensure you have a reliable internet connection
- ☐ Use the chat feature within the telehealth platform
- ☐ Complete any requested lab work prior to appointment to discuss with doctor
- ☐ Ask your doctor about checking your vitals ahead of time (temperature, pulse rate, and blood pressure)
- ☐ Keep an eye out for a text message or email from your doctor that includes a link to your session



It is important to keep up with appointments and routine testing.

Notes from my appointment:

Date:
