

GET UNCOMFORTABLE

WITH LUPUS NEPHRITIS



ASK YOUR DOCTOR THE **UNCOMFORTABLE** **QUESTIONS** ABOUT LUPUS AND YOUR KIDNEYS

“

Getting routine tests is not my favorite thing. Peeing in a cup and getting poked with needles can be really uncomfortable. But I've learned to embrace these uncomfortable moments because I know they could save my life. Peeing in a cup sucks, but kidney failure is way worse.

– Toni Braxton, Entertainer and Entrepreneur, Real person living with lupus

”

Prioritizing your kidney health might be uncomfortable, but the reality is that **up to 30% of people who live with lupus nephritis may experience kidney failure, which can lead to dialysis or even a kidney transplant.** Luckily there are steps you can take now—like using this discussion guide and bringing your own questions to your next doctor appointment to talk about lupus nephritis.

MANAGING LUPUS IS HARD BUT **PROTECTING YOUR KIDNEY HEALTH** IS WORTH IT!

WHERE ARE YOU IN YOUR JOURNEY?

Living with Lupuspg. 2

Newly Diagnosed with Lupus Nephritispg. 3

Established Lupus Nephritispg. 4

Preparing for Your Doctor's Appointmentpg. 6

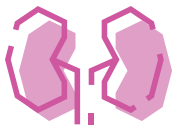
GET UNCOMFORTABLE

WITH LUPUS NEPHRITIS

LIVING WITH LUPUS

Lupus nephritis is a serious, silent and common complication of lupus that up to **50% of people with lupus may go on to develop**. If left untreated, it can cause irreversible kidney damage and other serious complications.

Being prepared for your appointments and staying on top of routine testing is critical in monitoring your kidney health. Get uncomfortable at your next appointment by bringing this guide and your questions to speak with your doctor about your kidney health.



WHY IS PRIORITIZING YOUR KIDNEY HEALTH SO IMPORTANT?

- Why are the kidneys so important?
- Why is it so serious when lupus affects the kidneys?



WHAT DO I NEED TO KNOW ABOUT TESTING FOR KIDNEY INVOLVEMENT?

- Why is it so important for people to get routine urine and blood tests and what will the results of these tests tell me?
- If I don't show any signs of lupus nephritis now, how often should I be tested for kidney involvement in the future?



HOW WILL I KNOW IF I HAVE LUPUS NEPHRITIS?

- What is my risk of developing lupus nephritis?
- If early symptoms of lupus nephritis are silent or hard to notice, how can I tell if my kidneys have been affected?



GUIDELINES RECOMMEND THAT PEOPLE LIVING WITH LUPUS GET A URINE TEST AS OFTEN AS ONCE EVERY 3 MONTHS.

BE YOUR OWN HEALTH ADVOCATE – TIPS FOR YOUR NEXT APPOINTMENT:

- ✓ Write down your symptoms over time and any changes between appointments
- ✓ Organize recent results from urine tests, blood work and/or lab tests. Keeping track of the levels of protein in your urine each visit is crucial to managing lupus nephritis. **Your doctor will likely aim for protein levels to stay below 0.5 grams per day.**
- ✓ Keep track of your medical appointments and hospital visits
- ✓ Take a friend or family member with you to your appointment
- ✓ Bring a list of all your medications (including vitamins and supplements)

GET UNCOMFORTABLE

WITH LUPUS NEPHRITIS

NEWLY DIAGNOSED WITH LUPUS NEPHRITIS

Choosing to prioritize your kidney health might be uncomfortable, but the reality is that **up to 30% of people who live with lupus nephritis may experience kidney failure, which can lead to dialysis or even a kidney transplant.**

Being prepared for your appointments and staying on top of routine testing is critical in monitoring your kidney health. Get uncomfortable at your next appointment by bringing this guide and your questions to speak with your doctor about your kidney health.



WHY IS PRIORITIZING YOUR KIDNEY HEALTH SO IMPORTANT?

- Why are the kidneys so important?
- Why is it so serious when lupus affects the kidneys?



WHAT DOES MY DIAGNOSIS MEAN?

- How can you tell how severe my kidney damage is and will become?
- What challenges, symptoms, or complications can I expect in the coming months and years?



HOW CAN I BEST MANAGE MY LUPUS NEPHRITIS?

- How might lupus nephritis affect my lifestyle, diet and life plans? Do you have any suggested changes?
- What are my treatment options, and what are the benefits and risks of each?
- Why is it so important for people to get routine urine and blood tests and what will the results of these tests tell me?
- How often should I come to see you to monitor my treatment and kidney health?



GUIDELINES RECOMMEND THAT PEOPLE LIVING WITH LUPUS GET A URINE TEST AS OFTEN AS ONCE EVERY 3 MONTHS, WHILE THOSE WITH ACTIVE LUPUS NEPHRITIS ARE TESTED AS OFTEN AS MONTHLY

BE YOUR OWN HEALTH ADVOCATE – TIPS FOR YOUR NEXT APPOINTMENT:

- ✓ Write down your symptoms over time and any changes between appointments
- ✓ Organize recent results from urine tests, blood work and/or lab tests. Keeping track of the levels of protein in your urine each visit is crucial to managing lupus nephritis. **Your doctor will likely aim for protein levels to stay below 0.5 grams per day.**
- ✓ Keep track of your medical appointments and hospital visits
- ✓ Take a friend or family member with you to your appointment
- ✓ Bring a list of all your medications (including vitamins and supplements)

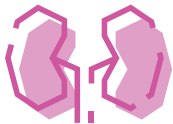
GET UNCOMFORTABLE

WITH LUPUS NEPHRITIS

ESTABLISHED LUPUS NEPHRITIS

Choosing to prioritize your kidney health might be uncomfortable, but the reality is that **up to 30% of people who live with lupus nephritis may experience kidney failure, which can lead to dialysis or even a kidney transplant.**

As you move further along in your journey, you may develop new symptoms, experience changes in your daily routine, or require additional testing. Being prepared to your appointments and staying on top of routine testing is critical in monitoring your lupus nephritis. Bring this discussion guide and a list of your questions to your next appointment to prioritize your kidney health.



WHY IS PRIORITIZING YOUR KIDNEY HEALTH SO IMPORTANT?

- Why are the kidneys so important?
- Why is it so serious when lupus affects the kidneys?



HOW IS MY TREATMENT GOING?

- Do I need to add, remove or adjust my medications?
- Why is another treatment being added, and what are the benefits, risks and possible side effects of this medication?
- Has my prognosis changed at all?



WHAT ELSE CAN I DO TO MANAGE MY LUPUS NEPHRITIS??

- Why is it so important for people to get routine urine and blood tests and what will the results of these tests tell me?
- How often should I come to see you to monitor my treatment and kidney health?
- 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?
- Have you been interacting with the other doctors or specialists who treat me?



GUIDELINES RECOMMEND THAT PEOPLE LIVING WITH LUPUS GET A URINE TEST AS OFTEN AS ONCE EVERY 3 MONTHS, WHILE THOSE WITH ACTIVE LUPUS NEPHRITIS ARE TESTED AS OFTEN AS MONTHLY



It's time to get real. Lupus nephritis patients have many odds against them, but we do have the power of choice. We can do our part to show up and be momentarily uncomfortable in hopes of better health, or worse off because we put ourselves last.

- Gabrielle, diagnosed with lupus nephritis in 2009

GET UNCOMFORTABLE

WITH LUPUS NEPHRITIS

ESTABLISHED LUPUS NEPHRITIS CONT'D

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

- 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

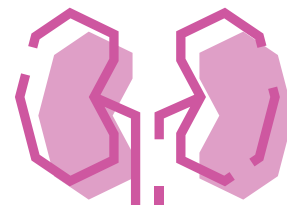
BE YOUR OWN HEALTH ADVOCATE – TIPS FOR YOUR NEXT APPOINTMENT:

- ✓ Write down your symptoms over time and any changes between appointments
- ✓ Organize recent results from urine tests, blood work and/or lab tests. Keeping track of the levels of protein in your urine each visit is crucial to managing lupus nephritis. **Your doctor will likely aim for protein levels to stay below 0.5 grams per day.**
- ✓ Keep track of your medical appointments and hospital visits
- ✓ Take a friend or family member with you to your appointment
- ✓ Bring a list of all your medications (including vitamins and supplements)

GET UNCOMFORTABLE

WITH LUPUS NEPHRITIS

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 the 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



When it comes to lupus nephritis, what you don't know can hurt you. I'm hopeful that stepping into the uncomfortable spaces of lupus nephritis, will be both empowering and life-changing. Your kidneys might even thank you later.

– Monique, diagnosed with lupus nephritis in 2010

GET *UNCOMFORTABLE*

WITH LUPUS NEPHRITIS

APPOINTMENT NOTES

DATE:

[illegible]

So much of life with lupus nephritis is unpredictable, but the status of our kidney health doesn't have to be. It's up to us to take those necessary steps no matter how uncomfortable they are to ensure we're doing everything we can to maintain our health.

- Tiffany, diagnosed with lupus nephritis in 2015

