

# A GUIDE TO LIVING WITH LUPUS



**If you've been diagnosed with lupus, you may have many questions about what's ahead. But let's start here: You aren't alone—and you can live a fulfilling life.**

Inflammation can harm the body's organs and is at the root of many of the uncomfortable symptoms associated with lupus. Thus, lupus can make everyday living a challenge. You may find it's a struggle to live, work, learn and play in the ways you did previously. Identifying new ways to adapt will allow you to address your changing needs.

Your support system will be important, so here's a guide about what you may need to help others help you. Navigate your journey with this resource, which includes suggestions for how to share your diagnosis with your loved ones and how to adjust your lifestyle and working habits to help make you more comfortable in the days to come.

## TALKING WITH LOVED ONES ABOUT LUPUS

**In life, it's important to surround yourself with people who love and support you. When you're living with lupus, that becomes even more important.**

Your support system is essential. So, how can you explain your diagnosis to those you love? Sharing any medical diagnosis can be difficult, particularly when you're struggling to come to terms with the diagnosis yourself. These tips may be helpful:

- **Break it down in basic terms.** With help from resources provided by organizations such as the Lupus Foundation of America or the National Institutes of Health, along with your medical team, talk with loved ones about lupus in the simplest terms possible. Explain how it may affect your body and what visible symptoms loved ones can watch for.
- **When sharing with kids, ask for help.** Understanding a medical diagnosis and handling the fear and anxiety it can cause is difficult for adults. It can be even harder for kids. Talk with your kids' pediatrician, school counselor or a religious leader about how best to share difficult information.
- **Find support for your support system.** Your spouse or significant other is your partner. But even the strongest of relationships can be tested by a challenging medical diagnosis like lupus. Consider seeking couples therapy to help navigate the challenges ahead and support a healthy relationship.



## ADAPTING YOUR HOME LIFE

**Every case of lupus is different. Many people with the condition experience periods where they feel well and then periods where the condition flares up.**

These “flares” can vary in severity and cause symptoms affecting different parts of the body, including extreme fatigue, joint pain, difficulty breathing and headaches.<sup>1</sup> Because how you feel may vary day to day, the normal ebb and flow of the household will need to change accordingly.

### START WITH THESE BASICS:

- **Give yourself time to rest and recoup.** Even if you normally consider your house a respite from the craziness of the world, you may find you need time now to rest from even the strains of the household. Create a routine that gives you that time and space.
- **Reassign household chores and responsibilities.** You may be able to continue handling your normal household responsibilities when you're experiencing remission, but during flares, someone else may need to take over. During a period when you're feeling well, take a few minutes to chat as a family and divide up tasks for those times.
- **Let others help.** If friends and family offer to help with household tasks, like mowing the lawn or picking the kids up from school, don't feel guilty about taking them up on the offer. But when having others around feels like a burden rather than a help, follow your instincts and take a raincheck.
- **Learn to say “no.”** As you learn to navigate your symptoms, you may simply be unable to participate in many activities, even the ones you typically enjoy. Create boundaries that support your health. Doing so will allow you conserve energy for what you deem most important.



## MAKING IT WORK AT WORK

**Before you received a lupus diagnosis, you were probably already experiencing symptoms that made everyday life and your work difficult some days. Will you be able to keep working?**

While working with lupus looks different for everyone, it can be done. Changes and adaptations can help you continue to do it successfully in the future. Similar arrangements can be helpful for those in school, as well.



### ACKNOWLEDGE THAT WORK WILL BE DIFFERENT

Regardless of your individual responsibilities, you will likely need to implement some changes moving forward. The first step in seeking the adaptations you need is acknowledging to yourself that you may need them at times.

Your needs are likely to change as time goes along, particularly when your symptoms flare. Keep that in mind and remember that these adjustments will help you get your work done and put you in a position for success while supporting your health.

### TALK THROUGH YOUR NEEDS WITH YOUR HR TEAM

You are entitled to “reasonable accommodations” under the Americans with Disabilities Act.<sup>2</sup> Before talking with your company’s human resources representative about your diagnosis and needs, first think through what you might need to be successful at your job.

This will depend a good bit on the symptoms you experience. If you have headaches that seem to be triggered by lighting, for example, you may need a workspace that uses dimmer lighting or has access to natural light from the window. If you experience fatigue frequently, you may need flexibility in determining your work hours or more breaks during the workday. If joint pain is a problem, you may want a supportive cushion for the seat or back of your chair to help with posture.



## LUPUS AND MENTAL HEALTH: WHAT YOU SHOULD KNOW

**Lupus causes inflammation in the body, which can wreak havoc on your physical health. But it can also impact your mental health.**

When you have lupus, you can experience ups and downs in your mood and mental state. That’s to be expected when managing any type of chronic condition, lupus included.

Beyond these normal fluctuations in emotions, though, having lupus can also increase your risk of developing mental health conditions, such as depression. Depression is especially common and persistent among those who have systemic lupus erythematosus, the most common form of the disease.<sup>3</sup>

Because of this, you want to pay close attention to how you’re feeling—not just physically, but emotionally and mentally, too. Keep an eye out for common signs of depression, including feelings of hopelessness, intense sadness, changes in appetite, increased irritability, crying, diminished self-esteem, a lack of interest in normally enjoyable activities and a lack of energy.<sup>4</sup>

Occasionally experiencing any of these symptoms is a normal part of being a human being, but if they stick around for at least a couple weeks, ask your medical provider about a depression screening.



## STAY AHEAD OF DISEASE ACTIVITY CHANGES

Because there is no cure for lupus, it's important to take an active role in managing your disease with routine monitoring.

AVISE SLE Monitor is an advanced lupus monitoring test that can help you proactively manage your disease. This test helps you and your doctor get a more accurate picture by tracking your biomarker levels to detect any changes in your disease activity and determine how it may be affecting your body. This test can help manage symptoms, track flares and gauge the effectiveness of your treatment plan, providing your physician with the most

accurate information available in an effort to mitigate disease progression.

You may be able to tell when you're experiencing a flare simply based on your symptoms, but without proper lupus monitoring tests, things like early signs of kidney inflammation can be overlooked.

**[Send your doctor information about AVISE SLE Monitor so they can determine if this test is right for you.](#)**

## TAKING CARE OF YOUR WHOLE HEALTH

Live better by taking good care of the connection between your body and your mind.



**Create a self-care routine.** Incorporate time each day for yourself—and focus on habits and hobbies that bring you joy. This can include anything that calms your mind and your body, such as listening to music, taking a bath, going for a walk, meditating or doing a puzzle. You may also consider taking the **AVISE SLE Monitor** test at your follow-up visits with your provider to give you the most accurate information available about your disease.



**Stay active.** You probably know that practicing healthy lifestyle habits can help you physically. But those same lifestyle habits can give your mental health a boost, too. When you're able, make it a point to move your body. Exercise is known to reduce stress and anxiety.<sup>5</sup>



**Prioritize rest.** Aim for seven to nine hours of quality sleep.<sup>6</sup> You may also need to rest more frequently throughout the day. Schedule short naps into your day if you find they help your mental state.



**Stay engaged.** While you may not be able to get out and about as frequently, particularly when you experience a flare, make it a point to socialize and maintain your relationships. Talking with friends and family can keep you from feeling socially isolated, which can harm your overall health.<sup>7</sup>



**Be kind to yourself.** Living with any type of chronic health condition can be difficult at times. Give yourself grace, especially on the hard days. Practice living in the moment and celebrate even the smallest joys!



**Develop a partnership.** By establishing a strong relationship with your care team, which includes your rheumatologist, you can optimize communication and ongoing well-being and minimize isolation.

Looking for other helpful resources on navigating the effects of lupus? Our library of content may help.

### References

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