

CARE PARTNER TOOLKIT

Help Us Solve
The Cruel Mystery

LUPUS®
FOUNDATION OF AMERICA

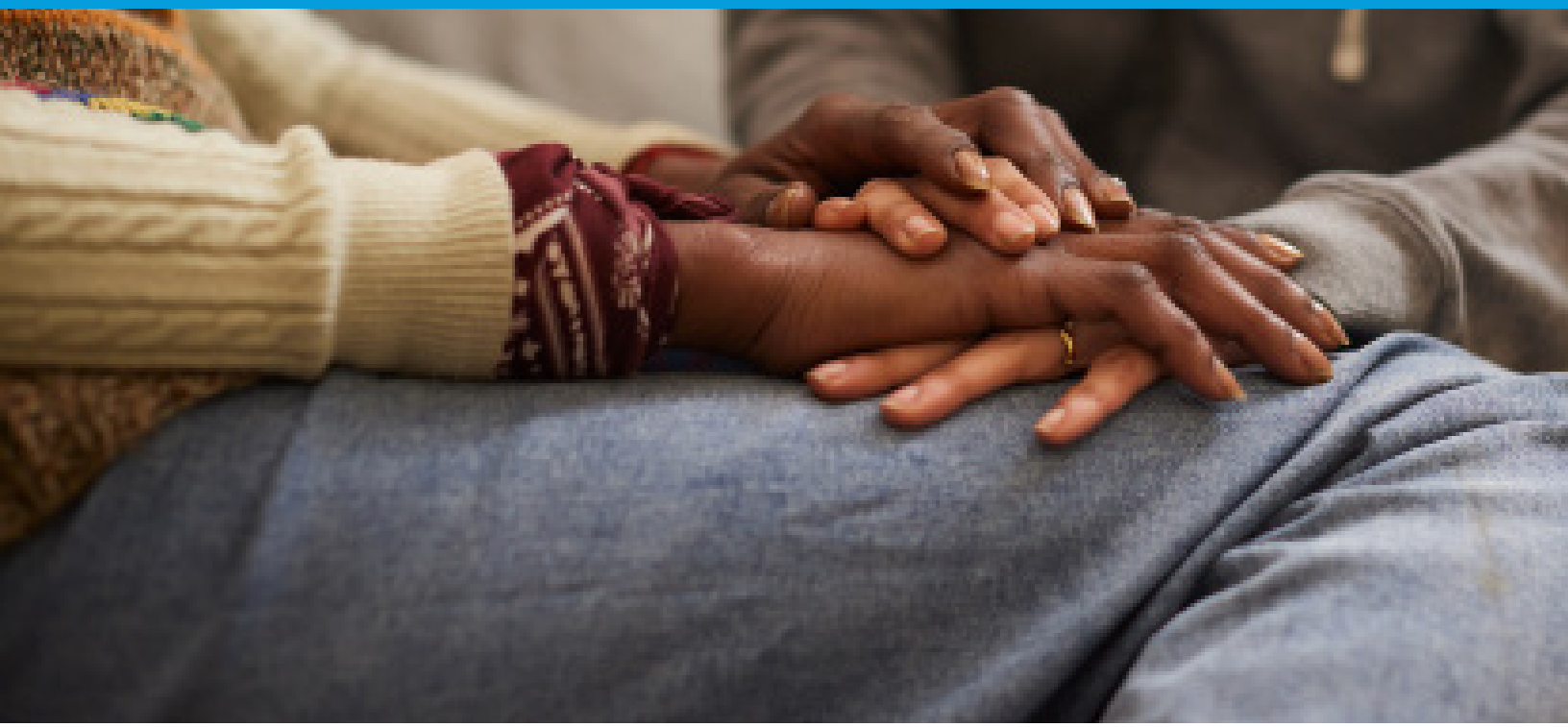


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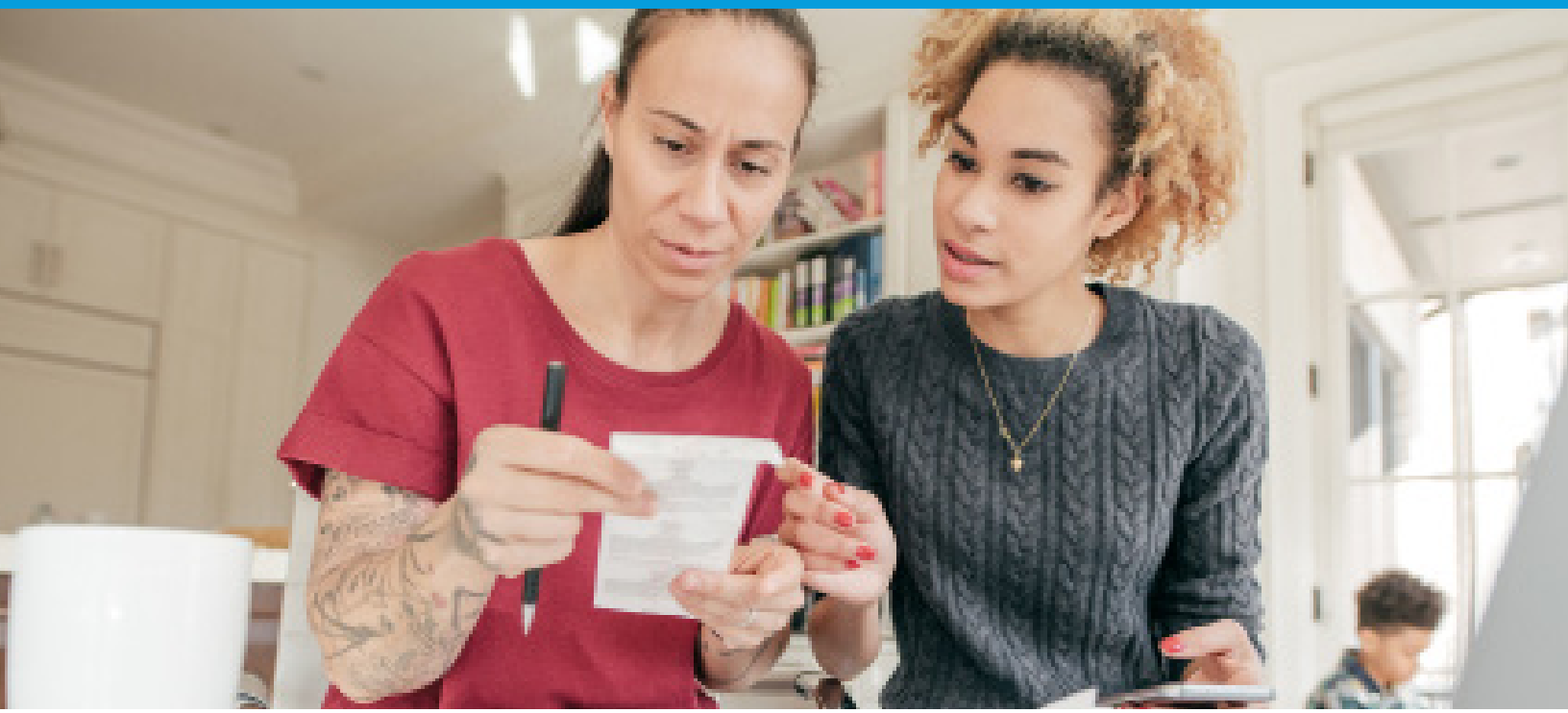
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HOW TO USE THIS TOOLKIT

This toolkit contains information to support care partners (or caregivers) of people with lupus. You can use it to learn more about ways to support your loved one with lupus, get advice for looking after your own well-being, and discover other helpful resources for navigating your loved one's lupus journey.

Getting Started as a Care Partner: Quick Resources

In addition to the detailed information in this toolkit, here are some other resources that can help you get started right away as a care partner:

Lupus Support Groups

Lupus.org/Resources/Find-support-near-you

Connects people with lupus to local and online support groups where they can share experiences and find encouragement.

Resources for Caregivers

Lupus.org/Resources/For-caregivers

Provides caregivers with tools, education, and support for caring for someone with lupus while also taking care of themselves.

National Resource Center on Lupus

Lupus.org/Resources

Offers reliable, up-to-date information and resources about understanding, diagnosing, treating, and living with lupus.

BEING A CARE PARTNER FOR SOMEONE WITH LUPUS



Are you a caregiver or care partner for a child or teen with lupus?

The information in this toolkit is primarily intended for care partners of adults with lupus.

If you help care for a child or teen with lupus, some of this information may be useful to you. You can also find information about lupus in children and teens in this dedicated resource: Children and Teens **Lupus.org/Resources/Children-and-teens**.

What does it mean to be a care partner for someone with lupus?

A care partner (sometimes called a caregiver) is someone who helps a loved one navigate and manage a chronic (long-term) health problem.

Being a care partner doesn't mean taking care of a loved one's every need — it means providing someone with practical and emotional support when they need it.

Care partners assist their loved ones in a variety of ways. When it comes to lupus, being a care partner may include helping a loved one:

- Navigate doctor's appointments and health insurance
- Complete daily living tasks (like cooking, cleaning, or doing yard work)
- Track their medicines and supplements (like vitamins or minerals)
- Learn more about lupus
- Manage their finances or legal matters
- Find ways to cope with the impacts of their disease

Your Loved One's Needs May Change

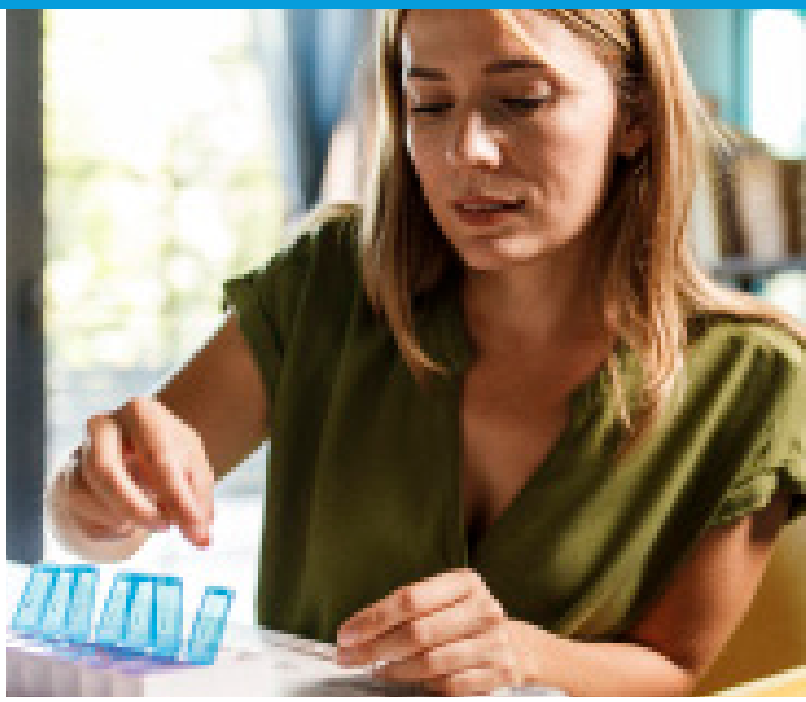
Lupus is characterized by flares (periods when lupus symptoms get worse) and remission (periods when symptoms improve). That means a person's support needs might change depending on how they're feeling, which symptoms are bothering them most, and their energy levels.

On a practical level, that means that sometimes, your loved one may need more help (or a different kind of help) than usual.

Here's another resource that can help you navigate lupus with your loved one: Living Well with Lupus: Tips for Loved Ones **Lupus.org/Resources/Living-well-with-lupus-tips-for-loved-ones**.

A person's support needs might change depending on how they're feeling, which symptoms are bothering them most, and their energy levels.

HELPING YOUR LOVED ONE WITH LUPUS



There are many ways you can help a loved one with lupus — and keep in mind that no 2 people with lupus have the exact same support needs. Everyone with lupus has a unique experience.

Ways to Support Your Loved One

Figuring out how best to support your loved one starts with a conversation. Then, you can think about what you're able to help with.

Start with a Conversation

Identifying ways to help your loved one starts with learning more about their experience with lupus, which symptoms are most bothersome, and what type of help would be most useful.

You could ask:

- Which symptoms have been bothering you most lately?
- How has it been balancing lupus with your job or school?
- Are you happy with the lupus treatment you're getting from your doctor?
- Is your lupus making it hard to keep up with chores or yard work?
- What could I do to help out?

Keep in mind that your loved one may not be comfortable asking for help. It might help to give suggestions of ways you could support them. You could say:

- I'd love to prep some meals and help stock your freezer for days when you don't feel like cooking.
- If you'd like support at your next doctor's appointment, I can come and help take notes. Or I could help you prepare a list of questions to ask at the appointment.
- Would you like me to do some reading about that new medicine you're interested in trying? I can share what I learn.
- I can help you find a support group for people with lupus, in case you'd like to talk about your experience with other people who've been there.

Think Through What You're Able to Do

It's possible that your loved one might need a type of support that you're not able to offer or that you don't feel comfortable offering. For example, depending on your relationship with your loved one, you might not feel comfortable helping manage their finances. Or your own schedule, health, or commitments might make it impossible to help at certain times or with certain tasks.

Your boundaries and bandwidth matter, just like your loved one's needs. If there's something you don't feel you can help with or if you just aren't sure how to help, talk with your loved one. You could try saying something like:

- I'm not sure I'm the right person to help you sort out your medical bills.
- I want to help out, but my work schedule makes it hard to find time to help with your yard work.

If you're able, you could offer other ways to help them get the right help. For example, you could say:

- Have you thought about calling the billing department to ask some questions about your invoice? I can help you find their phone number.
- What about your cousin who works in accounting? Do you think she might be able to look these bills over with you?

Or you could ask if they'd appreciate another type of support that you're better able to offer. For example:

- Would it be helpful if I did some grocery shopping for you on my way home from work instead?
- What if I picked your kids up and took them out for the afternoon so that you can focus on what you need to get done and have some time to rest?

It can be hard to say no to a loved one or feel like you can't give them what they need. Remember that your needs matter, too. And your loved one likely doesn't want you to feel uncomfortable or overextended.

Types of Support

Being a care partner for a loved one with lupus can involve providing emotional support, helping out with daily living tasks, or helping your loved one make decisions about their medical care.

Here are some ideas and resources that can help you partner with your loved one to manage their care.

Learn About Lupus

Educating yourself about lupus is an impactful way to support your loved one with lupus. It can help you know what to expect and better empathize with your loved one about what they're experiencing.

It also helps to unburden your loved one from having to explain their disease to you. Since lupus isn't very common, many people with lupus find that they often have to educate others about their disease. This experience can be tiring and can even make people with lupus feel isolated.

What's more, many people with lupus face stigma from people who don't understand the disease. For example, some people believe lupus is contagious (it isn't) or that only younger adult women get lupus (men, children, and older adults can get lupus, too).

You don't have to become a lupus expert. But taking the time to learn the basics can signal to your loved one that you're in their corner.

These resources are a good starting point for learning about lupus:

- What is lupus? **Lupus.org/Resources/What-is-lupus**
- Lupus Symptoms **Lupus.org/Resources/Common-symptoms-of-lupus**
- Diagnosing Lupus **Lupus.org/Resources/Diagnosing-lupus-guide**
- Treating Lupus: A Guide **Lupus.org/Resources/Treating-lupus-guide**
- Impact on Daily Life **Lupus.org/Understanding-lupus/Impact-on-daily-life**

This page is a great resource for those with lupus:
Living Your Best Life with Lupus Lupus.org/I-have-lupus

You can also encourage your loved one to learn more about lupus. Understanding lupus can be an important part of accepting and managing the disease.

Offer Emotional Support

Living with lupus can be a difficult, frustrating, and isolating experience. It's normal for people with chronic diseases like lupus to feel sad, helpless, or uncertain about the future.

Many people with lupus also experience more serious mental health impacts, including depression or anxiety.

As a care partner, you can be an important source of emotional support for your loved one.

Here are some strategies you can use to give them support.

Check in often. Let your loved one know that you're thinking about them, and ask them how they're feeling. Practice active listening — for example, by making eye contact and asking questions — to help them feel heard and cared for.

Create space for negative feelings. If your loved one shares feelings of sadness, frustration, or worry with you, acknowledge those feelings. For example, you can say, "That sounds difficult. I'm here for you." Try to avoid saying things like, "Just stay positive!" or "Things could be worse!" Although these phrases may seem like positive sentiments, they can also make people with lupus feel guilty or ashamed of their negative feelings. Keep in mind that you don't need to come up with a solution for your loved one. Just listening and offering support is helpful.

Be patient with your loved one. Many people with lupus struggle with symptoms like fatigue (feeling very tired all of the time) or pain that can make it hard for them to show up the way they'd like to in their relationships. For example, your loved one might need to cancel plans when they're not feeling well or might need to take more time for themselves to rest and recover. Try to be understanding if this happens.

Let them know you care. Offering emotional support to someone with lupus can be as simple as saying, "I'm sorry you're going through this. I care about you, and I'm here for you."

Practice Open and Constructive Communication

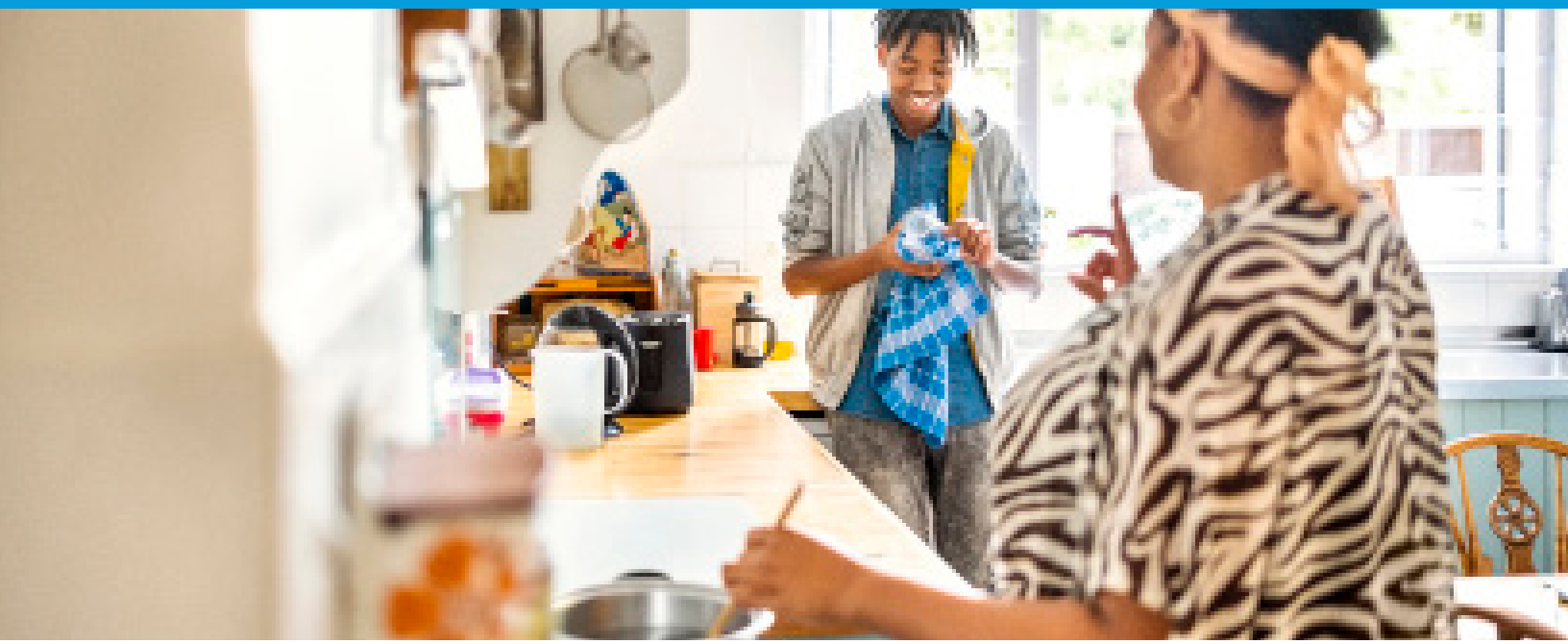
A lupus diagnosis can put new pressure on your relationship with your loved one. Stress, changing roles, and new needs can get in the way of clear communication. That makes it even more important for you and your loved one to find constructive and healthy ways to process how lupus is impacting both of you.

When you are a care partner, it's normal to feel frustrated by the situation or by your loved one's needs. And it's also okay to talk about those feelings. But there's a difference between venting frustrations and having a productive conversation. Aim to keep conversations open, honest, and respectful, rather than a release of emotion that leaves things unresolved. If emotions start running too high, take a break and come back to it another day.

Working through hard conversations without veering into venting can help you strengthen and protect your relationship with your loved one.



Keep in mind that you don't need to come up with a solution for your loved one. Just listening and offering support is helpful.



Assist with Daily Living Tasks

If your loved one's symptoms affect their ability to do day-to-day activities, assisting with daily living tasks can be one of the most impactful ways you can offer support.

The best way to know how to help your loved one is to ask. Here are some common options that many people with lupus welcome.

Help with housework or yard work. Pain and fatigue can make it challenging for people with lupus to keep up with chores around the house. Cleaning their home, doing laundry, or taking care of their yard, if they have one, are all ways you might be able to help your loved one.

Offer to help with childcare. If your loved one has children, you could offer to help with childcare. For example, you could watch the kids while your loved one goes to doctor's appointments, or you could take them to after-school activities.

Run errands. Grocery shopping, picking up medicines from the pharmacy, and dropping books off at the library are all examples of ways you could help your loved one when their energy is low.

Prepare meals. Eating a variety of healthy foods (like vegetables and fruits, whole grains, healthy fats, and healthy proteins) is an important part of managing lupus. But many people with lupus struggle with finding the energy to cook. Consider dropping off a hot meal for your loved one or preparing some freezer meals they can pull out when they're not feeling up to cooking.

Get Involved in Their Medical Care

Many people find navigating their medical care to be challenging and overwhelming. For people with lupus, this can be especially true because they:

- See multiple doctors to help manage their lupus
- Have multiple medicines to keep track of
- Need to do regular tests, such as blood tests, to monitor their condition

People with lupus may also face additional challenges in getting the care they need, such as:

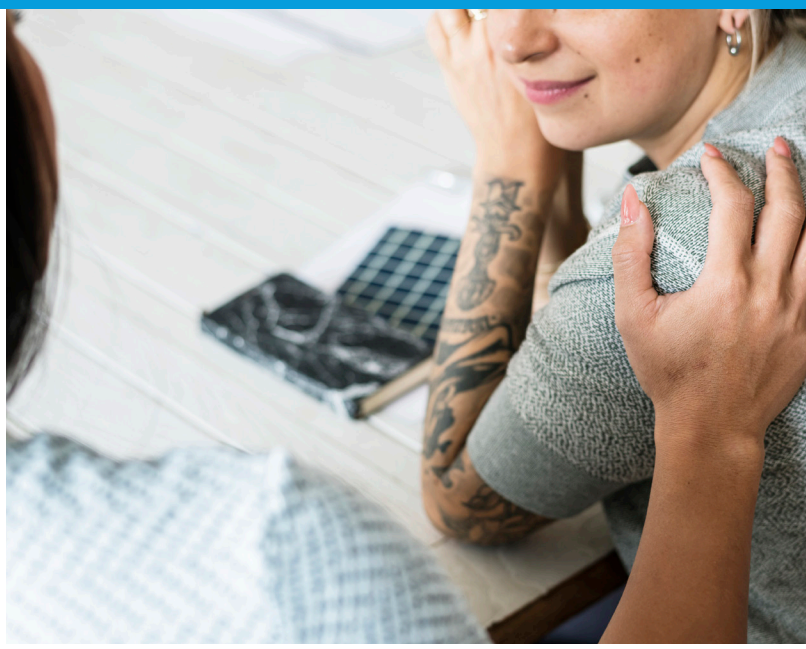
- Having their symptoms dismissed by doctors
- High medical costs
- Delayed diagnosis

Getting involved in your loved one's medical care can help make sure they're taking steps to manage their lupus and getting high-quality care. Here are some ways you can help:

- Offer to accompany them to doctor's appointments to help them advocate for themselves
- Help them think of questions to ask their doctor
- Take notes for them at appointments
- Assist them in finding a doctor they like and trust or in seeking a second opinion
- Keep track of their medicines and remind them to take their medicines on time
- Make note of their symptoms in a symptom log — write down when the symptom started, how long it lasted, and how much it bothered them
- Encourage them to explore different lupus treatments that might help, including complementary and alternative medicine or palliative care

Here are some resources to help you learn more about lupus treatment and care:

- Find the right lupus treatment plan for you **Lupus.org/Resources/Finding-the-treatment-approach-for-you**
- Treating Lupus: A Guide **Lupus.org/Resources/Treating-lupus-guide**
- Diet and exercise **Lupus.org/Resources/Diet-and-exercise**
- Complementary and Alternative Medicine for Lupus **Lupus.org/Resources/Are-there-complementary-and-alternative-medicine-therapies-for-lupus**
- Palliative Care for Lupus **Lupus.org/Resources/Palliative-care-for-lupus**



Prepare for a Medical Emergency

While it's not common, lupus can lead to a serious medical emergency. The risk is higher if your loved one has certain complications of lupus, like heart disease or kidney failure. Although life-threatening complications from medicines are rare, it's a good idea to be especially alert if your loved one has just started a new medicine (or changed their dose) until you and your loved one know how their body will react to it.

Being prepared for a medical emergency can help you act fast when it matters most, so your loved one can get lifesaving medical care.

Start by learning the warning signs of a medical emergency. If your loved one experiences any of these symptoms, call 9-1-1:

- Severe abdominal (stomach) pain
- Chest pain or shortness of breath
- Seizures
- New onset of fever or a body temperature that is much higher than normal
- A lot of bruising or bleeding anywhere on the body
- Confusion or mood changes

- A combination of symptoms such as severe headache with neck stiffness and a fever

Know where to find your loved one's important information, such as:

- Phone numbers for your loved one's emergency contacts
- Emergency medical ID (physical or digital tools, such as a card, bracelet, or phone app, that list your loved one's important health information for first responders)
- Health insurance cards
- A list of your loved one's medicines
- A list of contact information for all doctors or members of the healthcare team

Help your loved one be prepared for a hospital stay by putting together a "go bag" of necessary and familiar items, like:

- Comfortable clothing or a robe
- Slippers or sandals
- A novel, puzzle book, or other entertainment
- An extra phone charger
- Toiletries, such as a toothbrush, toothpaste, hair care products, or deodorant

It's also a good idea to know where the nearest hospital is and how to get there.

Help Navigate Finances, Legal Matters, and Health Insurance

Living with lupus can make your loved one's finances, legal situation, and health insurance status more complex. For example, your loved one may:

- Have trouble affording expensive lupus care or medicines
- Lose or earn less income because of symptoms that can make it harder to work, like fatigue, pain, and brain fog
- Wish to designate a friend or family member as their power of attorney (a legal status that gives someone the authority to make decisions on behalf of the person with lupus in certain situations)
- Choose to create an advanced healthcare directive (a legal document that states what type of medical care they want, if they're not able to speak for themselves)
- Need to choose between several different insurance plan options to get the best value
- Want to learn how to read their insurance plan's drug formulary to see if there are cheaper alternatives to their prescribed medicines
- Qualify for insurance through government-sponsored programs like Medicare or Medicaid

Here are some resources to help you and your loved one navigate financial, legal, and insurance complexities:

Financial

- Your Guide to Managing Finances **Lupus.org/Resources/Your-guide-to-managing-finances**
- Your Guide to Lowering Healthcare Costs **Lupus.org/Resources/Your-guide-to-lowering-health-care-costs**
- What to Know About Social Security Disability Insurance **Lupus.org/Resources/What-to-know-about-social-security-disability-insurance**

Legal

- End-of-Life Planning When You Have Lupus **Lupus.org/Resources/Endoflife-planning-when-you-have-lupus**
- Legal Concepts in Caregiving **Lupus.org/Resources/Legal-concepts-in-caregiving**

Insurance

- Health Insurance Guide for People with Lupus **Lupus.org/Resources/Health-insurance-guide-for-people-with-lupus**

- Getting Health Insurance When You Have Lupus **Lupus.org/Resources/Getting-health-insurance-when-you-have-lupus**
- What Caregivers Should Know About Health Insurance **Lupus.org/Resources/What-caregivers-should-know-about-health-insurance**

Keep Track of Important Information

Staying organized can make managing a chronic illness like lupus easier. As a care partner, you can support your loved one by helping them keep track of important information.

Here are some ways to help.

Encourage your loved one to set up their portal. Many doctor's offices and hospitals give patients the option to set up a portal that's connected to their electronic health record. Patients can use the portal to schedule appointments, see notes from their doctor's visits, view lab test results, and see their immunization record. Many doctors also use the portal to communicate with their patients, and most portals let patients send their doctor questions or report problems, such as side effects from medicines. Setting up a portal can make it easier for your loved one to access their important medical information quickly and securely.

Create a lupus-specific care file for your loved one. If your loved one has paperwork related to their lupus care, it helps to collect it all in one place. For example, if your loved one needs to change doctors, it's important for them to have information about when and how their lupus was diagnosed. Create a clearly labeled folder to store all your loved one's records. Consider ways to organize the records so they'll be easy to find later on, such as by date. And remember to store the care file somewhere safe and secure, especially if it includes paperwork with your loved one's sensitive information, like name, birth date, social security number, or medical record number.

Keep all your loved one's notes from doctor's visits in a single place. If your loved one likes to take notes at their doctor's appointments, it can help to keep them all in one place. For example, you can set up a notebook that your loved one can use for all of their doctor visits. That way, they can look back to see what they discussed at their previous appointment.

This page is a great resource for those with lupus:
Living Your Best Life with Lupus Lupus.org/I-have-lupus

TAKING CARE OF YOURSELF

Why Taking Care of Yourself Matters, Too

There's no denying that being a care partner to someone with a chronic disease like lupus can be taxing or even overwhelming at times. Feeling tired, frustrated, or downtrodden is a normal part of the care partner experience.

Many care partners struggle with balancing their own needs with those of their loved ones. You may even feel guilty about taking time to address your own needs. But it's important to keep in mind that **everyone** deserves rest. It's okay to prioritize your own well-being over your loved one's at times. In fact, you'll likely find that taking dedicated time for yourself and addressing your own mental, emotional, and physical health needs actually makes it easier for you to care for your loved one.

How to Take Care of Yourself

Knowing how to care for yourself isn't one size fits all, because we each have unique needs. Self-care for care partners may involve:

- Planning and taking breaks from care partner responsibilities
- Building a support system that you can rely on
- Prioritizing healthy habits

You may need to try different strategies to find what works to help you feel your best.

Take Breaks from Being a Care Partner

Having regular breaks from care partner responsibilities is an important part of taking care of yourself. Although it can be hard to prioritize time away from your loved one, doing so can help you avoid feelings of burnout (a state of emotional, physical, or mental exhaustion).

These warning signs can mean that you need a break:

- Feeling like you're constantly behind
- Having trouble at work or school
- Tension in your other relationships that's caused by your care partner responsibilities
- Experiencing stress or other health problems
- Feeling exhausted, on edge, depressed, or anxious

Scheduling breaks — even before you think you'll need them — is a way to help make being a care partner feel manageable and sustainable.

You can use a break to rest, get active, or do something that's just for you, like doing a hobby or meeting up with a friend.

It may help to see if another person in your loved one's life can step in to help while you take a break. For example, if you usually cut the grass or take care of the laundry, maybe there's someone else who can chip in to give you a break while still making sure your loved one gets their needs met.

Build a Support System for Yourself

Care partners need support systems too, just like people with lupus.

Having a support system can:

- Give you a social outlet outside of being a care partner
- Help you create connections with other people, including people who may be going through something similar
- Create a safe space for you to process your own emotions
- Provide support or help when you need it

There are many ways to build a support network for yourself. Here are some ideas.

Schedule regular check-ins or visits with your friends or loved ones. Being a care partner and

supporting someone with a chronic illness can be overwhelming, and it can be easy to lose touch with friends along the way. Having a standing date to check in with important people in your life can help you maintain those relationships. For example, consider having a weekly phone call or monthly coffee date with a friend or family member.

Join a club or try a class. Finding an outlet outside of being a care partner can be an effective way to cope with stress and give you an opportunity to meet new people. For example, you could consider attending a book club, joining a walking group, or signing up for an art class.

Find a support group for care partners. Many organizations — including the Lupus Foundation of America — organize support groups to help people impacted by lupus or other chronic diseases find community. A support group can be a way for you to share what you're going through with people who are familiar with lupus and to learn from their experiences. Some groups meet in person, while others meet online. You can find a support group using this resource: Lupus Support Groups **Lupus.org/resources/find-support-near-you**.

Get involved with community or faith organizations. Community or faith-based organizations can be great sources of support for care partners. They can give you a built-in network of people to rely on and provide moral support.

Talk with someone about your mental health. Being a care partner can be a stressful experience. If you're noticing a strain on your mental health (such as feeling depressed or anxious), talk with your doctor, a mental health professional, or a counselor about how you're feeling. They can offer support and make recommendations to help you feel better and look after your mental well-being.

Prioritize Healthy Habits

It can be hard to make time for healthy habits when you're supporting someone with lupus. But making time for physical activity, eating healthy, and getting enough sleep can go a long way in safeguarding your own health and well-being.

Remember to:

- Eat a variety of vegetables and fruits, whole grains (like whole-wheat bread or oats), healthy fats (such as olive oil, fatty fish, or avocados), and healthy proteins (like lean meats or poultry, beans, and low-fat dairy) each day
- Move your body most days of the week (for example, practice yoga, go for a walk, ride a bike, swim, or lift weights)
- Sleep 7 to 9 hours each night

It's okay if you don't follow healthy habits all the time. Keep in mind that small steps count — and healthy choices add up over time!

Some people may turn to unhealthy habits as a way to cope with stress (for example, by using tobacco, alcohol, or other drugs). These habits can have an extremely harmful effect on your health. If you're using substances as a way to deal with negative feelings, talk with your doctor about it. They can help you find healthy ways to cope.

It's also important to remember to keep up with your own doctor's and dentist's appointments and healthcare screenings. If you're not sure how often you should have a check-up or what screenings you need, talk with your doctor.

CARE TRACKER

NAME DATE

MEDICATION(S)

NAME OF MEDICATION	WHEN TAKEN	NOTES (Allergic reactions, etc.)

DIET AND NUTRITION

MEAL	NOTES/OTHER (Lack of appetite, food allergy, etc.)

DOCTOR APPOINTMENTS

DOCTOR NAME	REASON FOR VISIT	NOTES

NOTES

SYMPTOM TRACKER

Tracking your symptoms will help you and your doctor see how often you feel them. Doing this helps you remember how you felt and can help you and your doctor make a plan to feel better.

You can track up to 7 symptoms on this page following these instructions:

1. On the left side of this table, circle the symptoms you want to track. You can write 2 other symptoms.
2. Across the top of the table, you will see the days numbered from 1 to 14 (that's 2 weeks).
3. There are 2 ways you can use this tracker. Start with day 1.
   - Option 1- each day you have a symptom, color in the square.
   - Option 2- each day you have a symptom, rate the symptom on a scale from 1 to 5.

	DAY 1	2	3	4	5	6	7	8	9	10	11	12	13	14
DATES														
STRESS 														
PAIN 														
FATIGUE 														
BRAIN FOG 														
SKIN PROBLEMS 														

Notes

If there is anything important you want to remember, you can write it down here!

DATE	NOTE
DATE	NOTE
DATE	NOTE
DATE	NOTE

MEDICATION INFORMATION

MEDICATION		DOSAGE	FREQUENCY	DATE STARTED	DATE STOPPED	NOTES (PURPOSE, PRESCRIBING DOCTOR)
BRAND NAME	GENERIC NAME					

MEDICATION TRACKER

Writing down when you take your medicine will help you remember to take it the way you and your doctor decided is best for you. Use this tracker to help!

You can track your medicines on this page following these instructions:

1. On the left side of the table, write the name of each medicine that you take.
2. For each medicine, write in the time (or times) that you need to take it.
3. Across the top of the table, you will see the days numbered from 1 to 14 (that's 2 weeks).
4. Every time you take your medicine, color in the square for that time of day. Start with day 1.

MEDICINE	TIME OF DAY	1	2	3	4	5	6	7	8	9	10	11	12	13	14
Example: hydroxychloroquine 200 mg	*With breakfast*	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
	6:00PM	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

Great! Keep going and show it to your doctor.

YOUR LUPUS FLARE PLAN

This worksheet is designed for you to fill in with help from the doctor who's managing your lupus care and treatment. The term "rheumatologist" is used because rheumatologists are generally considered the experts in treating systemic lupus. However, you may be seeing a primary care provider, a dermatologist, or an immunologist.

1. If I think I'm having a flare, will my rheumatologist want to see me immediately?

- If yes, what should I tell the office appointment scheduler to make sure I'm seen as soon as possible?

- What should I do if I'm told that the next appointment is several weeks away?

2. What's the best way for me to explain my current symptoms to my rheumatologist, or to the physician assistant (PA) or nurse practitioner (NP)?

3. What will my rheumatologist do to get my symptoms under control as soon aspossible?

(For example, you may be told to start taking prednisone, to increase the dose of prednisone you're already taking, or go to the doctor's office for a cortisone shot in the buttock.)

4. Should I have blood and urine tests done during every flare?

- If yes, what is the procedure I should follow to have the tests ordered and done quickly?

5. How will I recognize symptoms of a lupus flare?

This is a list of common symptoms that could indicate a lupus flare. Check all that you're currently having:

- ☐ **Fatigue**
- ☐ **Joint pain**
- ☐ **Joint stiffness** upon waking
- ☐ **Hair loss**
- ☐ **Sores** in mouth or nose
- ☐ **Chest pain** that hurts upon breathing in
- ☐ **Fingers that turn blue and white when cold** (due to a circulatory condition called Raynaud's phenomenon)
- ☐ **Skin rash or sores**—several different kinds of rash can occur so see a dermatologist who is familiar with lupus for any new rash
- ☐ **Fever** *(Note: if you have fever see a doctor immediately to find out whether the fever is due to an infection or due to lupus. You can choose any one of these doctors: primary care provider, rheumatologist, urgent care center, emergency room.)*

6. The symptoms you had when you were first diagnosed with systemic lupus will often repeat themselves during lupus flares. List symptoms you had when you were diagnosed:

7. Health problems or symptoms that occurred after your diagnosis of lupus was made also may recur during lupus flares. List recurring problems and symptoms:

8. A symptom you've never had before might mean a lupus flare is underway.

A new symptom also could be due to something else (for example, a medication side effect or a viral illness). Write your new symptoms here:

9. There are certain flare triggers that are commonly experienced by people with lupus. Check all that you've experienced in the past two weeks:

- ☐ **Ultraviolet (UV) light exposure**
  (sunlight, snow, around water, stage lights, halogen lights, black lights, tanning beds, nail curing lamps, fluorescent lights, bactericidal lamps, arc lamps, mercury lamps, metal halide lamps, phototherapy lamps, welding equipment and plasma torches, counterfeit currency detectors, dental and printing polymerizing equipment)—Stay strict about UV protection. Find out more at resources.lupus.org and in books about lupus.

- ☐ **Cigarette smoke** (to include secondhand smoke)
  Avoid places where even second hand smoke is present. Find help quitting at smokefree.gov or call1-800-QUIT-NOW.

- ☐ **Sulfonamide antibiotics** such as trimethoprim-sulfamethoxazole (found in brand names Septra® and Bactrim®). Tell all healthcare professionals that sulfonamides are among your allergies, and always carry an up-to-date list of your medications and allergies that includes sulfonamides.

- ☐ **Echinacea herbal supplements**
  This herb is marketed as an immune booster. Because lupus is caused by an overactive immune system, anything that boosts the immune system should be avoided.

- ☐ **Alfalfa sprouts & mung bean sprouts**
  These contain an amino acid called L-canavanine which boosts the immune system. Make sure these aren't being added to food you eat out, and don't use them at home.

- ☐ **Stress**
  We can't completely get rid of stress, but we can take action to decrease stress. Lifestyle changes can help you avoid stressful situations and decrease stress in your life. Prioritize YOU!

- ☐ **Low vitamin D**
  Inflammation of lupus can be triggered if you have a low level of this vitamin in your blood. Ask your rheumatologist to check your vitamin D level regularly, and if you're told to take a vitamin D supplement, consider it as one of your most important lupus medications and take it as directed.

- ☐ **Not taking medications as prescribed**
  One of the most common reasons for a lupus flare is that the person isn't taking the medications as prescribed. Your rheumatologist will consider changing your treatment if you have a flare, because it will seem that the medicines aren't working. But that might be the wrong solution. It's always better to tell your doctor that you're not taking your medicines regularly, and explain the reasons, so that together you can come up with solutions.

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The Cruel Mystery

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