

Help Us Solve
The Cruel Mystery
LUPUSTM
FOUNDATION OF AMERICA

LUPUS FOUNDATION OF AMERICA CAREGIVER TOOLKIT

THIS GUIDE IS DEDICATED TO ALL THOSE WHO LIVE WITH THE DAILY
CHALLENGES OF LUPUS AND THE CAREGIVERS WHO SUPPORT THEM DAY
IN AND DAY OUT

—

This resource made possible in part through a gift in Memory of Gloria Lynn Belk and Georgia Wiggers Belk

*Gloria Lynn Belk (1945 - 1977) lived with lupus
Georgia Wiggers Belk (1923 - 2012) Gloria's mother and constant caregiver*

CAREGIVER TOOLKIT OVERVIEW

If you are a caregiver for someone with lupus, you are not alone. This toolkit is designed to provide you with guidance, support, and advice, whether you have been a caregiver for just a few days, or for several years.

This toolkit is organized into several sections:

SECTION I	Caring for Someone with Lupus	1
	<i>Who are caregivers?</i>	2
	<i>How you can help</i>	3
SECTION II	Taking Care of Yourself	7
	<i>Know your limits</i>	8
	<i>Make healthy choices</i>	9
	<i>Accept your feelings</i>	10
	<i>Learn to solve problems</i>	11
SECTION III	Managing Finances, Legal Matters, and Health Insurance	12
	<i>Managing your loved one's finances</i>	13
	<i>Do you have legal authority to make decisions?</i>	15
	<i>Become familiar with your loved one's health insurance</i>	16
SECTION IV	Preparing for Unexpected Events	21
	<i>Preparing for a medical emergency</i>	22
	<i>Finding a new doctor</i>	23
	<i>Loss of health insurance coverage</i>	24
	<i>Preparing for financial emergencies</i>	25
	<i>Five important documents you should have</i>	26
SECTION V	Caring for Children and Teens	27
	<i>Track your child's health and keep them involved and engaged</i>	28
	<i>Find a shoulder to lean on</i>	29
	<i>Understand the emotions caused by lupus and help your child express them</i>	30
	<i>Helping teens to take control of their health</i>	31
SECTION VI	Appendix: some helpful forms to keep you organized	34
	<i>Care File: important health information to keep handy</i>	35
	<i>Doctor Visit Tracker: staying organized during and after appointments</i>	42
	<i>Medications: keeping track of dosage, frequency, and dates</i>	43
	<i>Daily Care Plan: coordinating care among all caregivers</i>	44

SECTION I

Caring for Someone with Lupus

When a person with lupus develops serious health issues and can no longer function independently, someone may need to assume the role of caregiver. While doctors, nurses, and other medical staff are also considered caregivers, this guide will focus on family members or friends who assume the caregiving role.

WHO ARE CAREGIVERS?

CAREGIVING DEFINED

If you provide direct care and support to a person with lupus, you are likely a **caregiver**, regardless of your relationship to the person with lupus.

WHAT IS A LUPUS CAREGIVER?

A lupus caregiver is **someone who commits to providing direct care and support to a person diagnosed with lupus.**

WHO ARE LUPUS CAREGIVERS?

Caregivers may be **parents, a spouse, children, other family members, or friends.** In some cases, there may be more than one caregiver.

WHAT DOES A CAREGIVER DO?

Because each lupus diagnosis is so unique, **care needs and caregiving responsibilities may vary.** You may need to provide more help, such as day-to-day care (e.g., keeping track of medication administration); or, less frequent care (e.g., going to doctor visits with your loved one). One of the most important functions of a caregiver is to provide emotional support. Even if you play a small role in the day-to-day care of your loved one, you may still play a crucial role in their mental and emotional health.

HOW YOU CAN HELP

The more you know about lupus and how to cope with lupus, the better prepared you are to be a good caregiver. Understanding the disease can make the initial transition into caregiving a little less intimidating. It can also help you determine a caregiving plan that meets the specific needs of your loved one.

UNDERSTAND LUPUS

While learning about lupus is ongoing, here are some things you should focus on first:

Educate yourself

Educate yourself about the nature of lupus and the symptoms of the disease. For more information regarding lupus, refer to the “Get Answers” section on lupus.org.

Be open to change

Living with lupus usually requires certain lifestyle adjustments.

Be emotionally considerate

Feelings of sadness, helplessness, and uncertainties about the future are a normal part of living with chronic illness.

Be aware

Be aware of how lupus is affecting your loved one (physically and emotionally), and pay attention to changes in symptoms or physical conditions that may suggest a flare. Common symptoms that indicate a flare are ongoing fever not due to an infection, painful and swollen joints, an increase in fatigue, rashes, sores or ulcers in the mouth or nose, and general swelling in the legs. Some flares happen without symptoms. This is why it is important for a trained lupus doctor to regularly monitor your loved one’s health.

HELP YOUR LOVED ONE LEARN ABOUT LUPUS

Your loved one's understanding of the disease can make a difference in how you lend support and how they prefer to receive it. By working together to understand the disease, you can create a plan to cope with lupus.

Helping your loved one learn about lupus has other benefits too. Some people with lupus feel guilty about needing a caregiver and the demand that caregiving places on you. Learning more about the disease may help them understand that the impact of lupus may be too large for one person to deal with alone.

Going through the learning process together also strengthens your relationship. A strong relationship can help your loved one feel more comfortable receiving care, especially if decisions are made together about caregiving needs.

COMMUNICATE

It is normal to experience changes in moods, relationships, and activities within the family following a diagnosis of any illness. Through it all, caregivers can use good communication skills to respond appropriately and keep up a positive attitude. Healthy communication allows family members to connect with each other.

Here are some key points to remember:

Reach out

Reach out to others. It is a good way to gain support and share feelings.

Be open about your needs, and ask others for help.

Communicate

Communicate with your loved one in a positive way, but also be realistic and adjust to "a new/normal," instead of expecting "a return to normal." Make time to talk about this transition, and how it is affecting each of you.

Aim for a healthy exchange of information, which is different from venting emotions.

Talk about major problems caused by lupus, what is most feared about the disease, and your loved one's needs.

CREATE A CARE FILE

As a caregiver, one of the most important things you can do is create a care file for your loved one.

Whether you keep it in a binder, file folder, or entirely electronically, this file should:

Inform

Provide access to essential information.

Help

Help communication between your loved one and their providers.

Unify

Unify all important information in one place.

Reduce stress

Reduce stress knowing that all health and emergency information related to the care recipient is organized into one place.

Save time

Save time and energy. When the caregiver is unavailable, a well-maintained file can help others provide proper care for the person who is ill.

CARE FILE INFORMATION

The file should be organized in such a way that you can take it to doctor's appointments. It should be kept confidential and in a safe location.

Specific information about the person with lupus should include:

- Personal information (such as date of birth, identification, and insurance information)
- All current diagnoses and medical history
- Contact information for all doctors and other health care providers
- Dates of doctor visits and changes in treatment
- Names of medications, dosages, and any special precautions
- Emergency contacts

You can create this packet on your own, or you can use our care file forms, found in the Appendix. Forms for tracking doctor's visits and medications can be found in the Appendix as well.

DEVELOP A DAILY CARE PLAN

A daily care plan is a list of duties and responsibilities that address the daily and long-term needs of your loved one. It should be simple and descriptive. A good plan will provide instructions to those who share caregiving duties when the primary caregiver is unavailable. During stressful times, it can help avoid a potential crisis.

Keep in mind the following tips when creating your care plan:

Identify

Identify major problems and your loved one's health care needs.

Describe

Describe specific caregiving tasks and the necessary steps to complete these tasks.

Organize

**Organize caregiver tasks into categories (for example, health care or household).
Which tasks are a priority and non-negotiable?**

List

List key family members or friends who can help in an emergency situation.

Consider

Consider community organizations that may be helpful, especially in an emergency.

Be flexible

Allow for flexibility and change in the daily care plan.

You can create a daily care plan on your own, or you can use ours, found in the Appendix.

SECTION II

Taking Care of Yourself

Caregiver responsibilities can be overwhelming and draining, but taking care of yourself is one of the most important things you can do. The stronger you remain—physically and mentally—the more support you will be able to offer. To adequately give care, you must take care of yourself. In this section we will discuss four concrete ways that you can do so, including tips and advice for each one.

KNOW YOUR LIMITS

Sometimes it's hard to know when to stop. In addition to all of the things you need to do in your home, at work and with your family, you now have a new set of responsibilities. You may feel like there are more things to do than there are hours in the day, and that is perfectly normal. It's important for you to accept that you can't do it all, and that your personal health and wellbeing is just as important as the to-do list in front of you.

RECOGNIZING WARNING SIGNS

Be realistic about how much you can do and what you can't do, and pay attention to these warning signs:

- Do you often feel that no matter how much you plan or how hard you work, things are not getting done?
- Are your caregiving responsibilities interfering with your work, your relationships and your health?
- Do you feel exhausted and tense most of the time?

If you experience one or more of these warning signs, ask for assistance from others. Make a list and let others know what would be most helpful to you.

MAKE HEALTHY CHOICES

Caregiver stress is the daily physical and emotional “wear and tear” that comes with taking care of your loved one. The more stress you are under, the more strain you may feel on your mental and physical health. Building resilience (being able to recover) to help you “bounce back” from stressful times is self-nurturing and can have real health benefits.

CREATING HEALTHY HABITS

Follow these tips to build resilience through healthy choices:

Eat healthy

Schedule time to eat regularly and follow a healthy diet.

Exercise regularly

Exercise regularly to relieve stress and promote good health.

Drink in moderation

If you drink alcohol, drink in moderation.

Get enough sleep

Get enough sleep to recover from fatigue and re-energize. Your body needs rest to recover from stress.

Get regular checkups

Get regular checkups with your health care provider. Ask about the best diet and exercise routine for you.

Take time for yourself

Arrange for a family member or friend to stay with your loved one while you do so.

Stay connected

Stay connected with friends and plan to do something fun on a regular basis.

Take a stress management class

Take a stress management class to learn about coping techniques that may be helpful.

Take advantage

Take advantage of community resources for caregivers, such as respite or home health care.

Develop a positive attitude

There will be situations that you cannot control, and that’s OK!

ACCEPT YOUR FEELINGS

Caregiving can be an emotional roller coaster. You may feel angry about what is happening to your loved one. You may feel out of control, because your life has changed so much, and anxious, because you cannot “fix everything.” You may also have guilty feelings that come and go when you try to do more and more, but find that there are not enough hours in the day to get everything done.

When the future is uncertain and you are taking on the bulk of responsibilities, it is easy to feel alone and helpless. It’s important for you to realize that the best thing you can do to start feeling better is to *accept* your emotions. Strong emotions are a part of caregiving and if you don’t recognize and understand them, they can lead to burnout.

MANAGE YOUR EMOTIONS

Here are some tips to help you cope with your emotions in a healthy way:

Be aware of your feelings

Be aware of your feelings and accept them, as opposed to pushing them away. Expressing them appropriately is a healthy choice. Develop a support network just for you. Reach out to family, friends, and professionals like counselors, therapists, and other health care professionals with whom you can comfortably share your feelings and make sense of them.

Join a caregiver support group

Join a caregiver support group where you can safely and comfortably share your story with people who are having similar experiences. Many caregivers who attend support groups find hope and strength in these meetings.

Keep a journal

Keep a journal about your experiences and how they make you feel. Talk to your health care provider about any feelings of anxiety and/or sadness that won’t seem to go away.

Be open to seeking professional help

Be open to seeking professional help from a therapist or trained counselor. Professional counselors and therapists can provide exceptional support and guidance, in a safe and supportive setting.

Contact your local hospital

Contact your local hospital or a community wellness center for information about mental and emotional health.

Find some quiet time

Find some quiet time and reflect on your journey as a caregiver. You will find that there are successes in every story.

LEARN TO PROBLEM SOLVE

Problems don't follow the basic rules of politeness. They don't wait for the right time before they come knocking, or go away quietly if it isn't a good time for you. Caregiving can bring new challenges into you and your loved one's lives, and you will both need to work together to overcome them. Problem solving is about working through the details of a situation to reach the best possible results. The more organized and stepwise the process is that you create, the less stressful and overwhelming it will be for you.

STEPS TO PROBLEM-SOLVE

Here are some tips to help you manage challenges. Be sure to work through these steps in writing as well as in your head:

- STEP 1** Describe a particular problem or uncertainty. What are you most worried about?

- STEP 2** To understand the issue more clearly, talk to a family member or a friend about it. Others may interpret it differently and provide helpful information.

- STEP 3** Narrow down the best possible solutions. What information is most relevant to the problem?

- STEP 4** Write down all possible solutions.

- STEP 5** Of these solutions, what will help your loved one the most?

- STEP 6** Choose the best possible solution to the problem and list out what steps need to be taken.

- STEP 7** Put your plan into action.

- STEP 8** After you have put your plan into action, evaluate the results. Are you satisfied with the way things worked out? What might you do differently in the future?

SECTION III

Managing Finances, Legal Matters, and Health Insurance

As a caregiver, one of the most important things that you can do is ensure that your loved one's financial, legal and health insurance-related interests are protected.

MANAGING YOUR LOVED ONE'S FINANCES

As a caregiver, you may be involved in managing your loved one's finances or even planning for a secure financial future. When planning, be aware of current assets (cash, property and other items that can be converted into cash) and recurring bills. It's especially important to understand any financial changes due to increased medical costs.

Here are some tips to help you get started:

- Work together: collect information and documents (such as assets, bills, bank statements, loans, tax information, property deed, and investments) and schedule a time to review your loved one's overall financial situation.
- Determine if there are any items that should be addressed immediately.
- Set goals and determine a practical budget. Be sure to include a plan for upcoming costs.

CREATING A BUDGET

One of the most important things you and your loved one can do is create and follow a realistic budget. There are many resources available to help you create and track your budget.

What you use depends entirely on your own personal preferences. You can:

- Go the old fashioned route and use pen and paper.
- Create a detailed Excel spreadsheet.
- Use one of many free phone and computer applications, like Mint or GoodBudget, to create and track expenses.

FINANCIAL PLANNERS

Working with a professional may help your loved one feel more at ease sharing personal financial information. A personal financial planner or a legal financial advisor can help review current cash flow and monthly bills, look for tax savings, and provide advice on estate planning and investments.

How can you find a financial planner?

Contact your local bank

Contact your local bank to ask about financial planning services that they may offer.

Use a professional organization

Use a professional organization to get names of local financial planners. Here are some examples:

***National Association of Personal Financial Advisors
Financial Planning Association (FPA)***

Here are some important questions to ask when working with a financial planner:

- What specific services are provided and what is the cost?
- Is the person licensed? Registered with the state?
- What professional organizations do they belong to?

Be sure to explain why you are looking for assistance from a financial planner.

Schedule a face-to-face meeting. This can help determine a general sense of trust and may provide the opportunity to ask about the person's experience. If you or your loved one is not comfortable, interview another financial planner.

DO YOU HAVE LEGAL AUTHORITY TO MAKE DECISIONS?

Caregivers should be familiar with the legal documents that give someone authority to make decisions about health, financial, and legal affairs, on behalf of another person. These documents serve to protect your loved one's wishes and can grant authority for you to make certain decisions, as determined by your loved one.

DURABLE POWER OF ATTORNEY

A durable power of attorney is a **critical document that allows a designated person** (also known as the attorney-in-fact) to **make legal and financial decisions on someone else's behalf**. A durable power of attorney remains in effect even if the principal (your loved one) becomes mentally incompetent (unable to exercise sound judgment). It is different than a will and it becomes ineffective when the principal dies. The attorney-in-fact must manage and use assets only for the benefit of the principal.

ADVANCE HEALTH CARE DIRECTIVES

Advance health care directives are **written instructions about medical treatments and life-sustaining measures that a person wants, or does not want, if he/she becomes incapacitated**. These legal documents speak for persons who are not able to speak for themselves in the event of a serious accident or illness.

According to the American Bar Association, state laws vary regarding the appropriate documents to cover these situations. In all fifty states, a person is legally allowed to express his/her wishes for medical treatment in case of severe illness or injury, and to appoint someone to communicate for them in the event that they can't communicate for themselves. However, the names of these documents vary depending on the state. You may hear them called "living wills," "medical directives," "health care proxies" or "advance health care directives." You can find out more about advanced health care directives through your state's Attorney General's office or through your loved one's doctor. There are also a number of websites, such as Caring Connections (caringinfo.org), where you can download a state's specific advance health care directive.

DURABLE POWER OF ATTORNEY FOR HEALTH CARE

Because advance directives cannot describe all possible situations, a person may also choose to have a durable power of attorney for health care. A durable power of attorney for health care **allows your loved one to appoint someone (generally known as the health care agent or health care proxy) to make medical decisions about situations that are not included in an advance directive**.

BECOME FAMILIAR WITH YOUR LOVED ONE'S HEALTH INSURANCE

Health insurance (lupus.org/resources) covers an insured person's medical and surgical expenses. Whether they have private health insurance or public health insurance, like Medicare or Medicaid, it's important for you and your loved one to feel knowledgeable about your loved one's coverage. Review their health insurance policy together. You should have easy access to policy numbers, claim forms, and contact information. Keep a file with benefit summaries, any out-of-pocket costs that may occur, and insurance premium costs, for tax purposes and financial planning. If the technical language used in written policies is difficult to understand, discuss the policy with an insurance agent.

If your loved one does not have health insurance, this is a good time to research the different options available (lupus.org/resources), and to consider signing up.

INSURANCE INFORMATION THAT YOU SHOULD KNOW:

- Services that are covered and not covered in the policy.
- Prescription medications that are covered and not covered in the policy, including any medications that fall into special tiers.
- Whether the coverage applies to a specific network of doctors and hospitals.
- Whether outpatient services (services provided in a medical center without an overnight stay) are covered.
- Specific coverage limitations.
- Deductibles and out-of-pocket expenses (percentage of health care costs not covered under the policy), and annual insurance premiums, to help you with financial planning.
- Policies associated with long-term disability, long-term care, or life insurance, if your loved one requires it.
- Filing a claim (most policies include information about filing a claim).

MEDICARE

Medicare is a federal health insurance program, for people who are 65 or older, certain younger people with disabilities, and people with end-stage renal disease (ESRD).

Caregivers should be familiar with:

- **What Medicare covers and the different types of coverage**
- **The claims process**
- **Out-of-pocket costs that may occur**
- **Supplemental insurance plans**

More information regarding Medicare

Medicare is a federal insurance program that pays for medical care for people who qualify.

People who have been determined to be disabled and have been receiving disability benefits for at least 24 months qualify for Medicare. People with lupus who need long-term dialysis treatment for chronic kidney disease or require a kidney transplant will qualify for Medicare immediately after they are determined to be disabled. In general, Medicare pays 80 percent of reasonable charges. Some parts of Medicare are free, but some parts are not.

What are the different plans under Medicare?

Medicare Part A (Hospital Insurance) helps cover inpatient care in hospitals, including critical access hospitals and skilled nursing facilities (not custodial or long-term care). The taxes your loved one paid while he/she was working pays for this coverage, so services covered under Part A are free.

Medicare Part B (Medical Insurance) helps cover doctors' services and outpatient care. This coverage has a monthly premium.

Medicare Part C (Medicare Advantage) combines hospital and doctor coverage and is provided by private insurers. Medicare pays a fixed amount for a person's care every month to the companies offering Medicare Advantage Plans. These companies must follow rules set by Medicare. However, each Medicare Advantage Plan can charge different out-of-pocket costs and can have different rules for how a person receives services (such as whether a referral is required to see a specialist or whether only doctors, facilities, or suppliers that belong to the plan may be used for non-emergency or non-urgent care).

Medicare Part D provides prescription drug insurance. Private companies also provide the coverage. Beneficiaries choose the drug plan and pay a monthly premium. If a person joins a Medicare Advantage Plan, the plan will provide all of Part A (Hospital Insurance) and Part B (Medical Insurance) coverage. Medicare Advantage Plans may offer extra coverage, such as vision, hearing, dental, and/or health and wellness programs. Most include Medicare prescription drug coverage (Part D).

How to apply for Medicare

If your loved one is receiving Social Security Disability Insurance, he/she must wait 24 months from the time he/she was declared disabled before applying for Medicare (unless he/she has been diagnosed with end stage renal disease, as explained above, which makes a person eligible immediately). Non-disabled people become eligible for Medicare when they reach the age of retirement. Call 1-800-MEDICARE (633-4227) visit www.medicare.gov for information. However, people who want to apply for Medicare coverage only (e.g., they are working and do not intend to file for monthly retirement or spouse's benefits at this time) should call 1-800-772-1213 (TTY 1-800-325-0778) toll-free to arrange an appointment over the phone or in person at a Social Security office.

SOCIAL SECURITY DISABILITY INSURANCE

If the person you are caring for is already receiving Social Security disability insurance (SSDI) benefits or Supplemental Security Income (SSI) benefits (Medicaid), payment information should be carefully maintained to help with planning a financial budget and tax purposes. If not, then information about Social Security Disability benefits can be requested and added to your loved one's file. Applying for benefits will be less difficult when prepared.

According to Federal law, "Social Security pays disability benefits to you and certain members of your family if you have worked long enough and have a medical condition that has prevented you from working or is expected to prevent you from working for at least 12 months or end in death. "

The vast majority of applications for Social Security disability will be denied. Persons applying for disability should be familiar with the appeals process.

A Disability Starter Kit (ssa.gov) may be helpful.

A legal representative can help guide the process.

General information regarding Social Security Disability Insurance

Social Security Disability Insurance is the federal program, supported by payroll taxes, that pays benefits to people who cannot work due to a medical condition. In order to qualify, your loved one must have a medical condition that meets Social Security's definition of disability and is expected to last at least one year or result in death.

The person you are caring for will be considered disabled if they can provide medical evidence that they are unable to do the work that they did before and they cannot adjust to other work because of their medical condition(s). No benefits are payable for partial disability or for short-term disability.

Generally, to be eligible for disability benefits, a person must have worked long enough and acquired enough work credits. The number of work credits required will depend on the person's age when they became disabled. There are different eligibility rules for children under the age of 18.

How does the Social Security Administration determine if a person is disabled?

There are five steps along the path to being declared disabled:

STEP 1 Are you working?

In 2013, if you make more than \$1,040 in a month, you are presumed to be engaged in substantial gainful activity (SGA). This may make you ineligible for benefits. This amount changes from year to year and can be found on the SSA website.

STEP 2 Is your condition severe?

Your impairment(s) must significantly limit your ability to do basic work activities; for example: walking, sitting, seeing, and remembering.

STEP 3 Is your condition found in the list of disabling conditions?

Social Security maintains a Listing of Impairments for each of the major body systems. Lupus is listed under Immune System Disorders in [section 14.02](#).

STEP 4 Can you do the work you previously did?

If your condition is severe but not at the same or equal level of severity as a medical condition on the list, then Social Security must determine if your condition interferes with your ability to do the work you did previously.

STEP 5 Can you do any type of work?

If you cannot do the work you did in the past, Social Security will see if you are able to adjust to other work. They consider your medical conditions and your age, education, past work experience, and any transferable skills you may have. If you cannot adjust to other work, your claim will be approved.

How do I apply for social security disability?

You should apply for disability benefits (socialsecurity.gov) as soon as you become disabled. You can complete some or all of the forms online or you may call the Social Security Administration (SSA) toll-free at 1-800-772-1213 to schedule an appointment. Staff personnel at SSA office can assist you either in person or by phone.

Build your case:

You must be able to prove, by furnishing medical and other evidence, that your loved one is disabled by lupus (not just that they have lupus) and meets the Social Security definition of disability. Their doctor cannot “declare” that they are disabled. Your loved one and his or her doctor must provide evidence that proves lupus prevents him or her from engaging in any substantial gainful employment and that this condition is expected to last for a continuous period of at least twelve months, or result in death.

What to expect:

It can take between three and five months to obtain an initial decision. Almost two out of three applicants are denied benefits initially, and most people who file a written appeal (called “reconsideration”) also are denied. The third level appeal before an administrative law judge is most successful. More than 60 percent of denials are overturned at this stage, so you must be patient. You can improve your loved one’s odds of being approved for disability by building a solid case based on appropriate medical evidence. You may also want to consult with a disability lawyer to assist you through the process.

SECTION IV

Preparing for Unexpected Events

Emergencies and unexpected events require immediate attention. If you need to act quickly, being prepared saves time and protects your loved one. How do you start preparing for situations that require quick thinking and action? In this section, we discuss five types of events you should be prepared for.

PREPARING FOR A MEDICAL EMERGENCY

A medical emergency is a situation that poses a serious health risk and requires immediate help. People with lupus sometimes develop life-threatening complications. You should **be aware of symptoms that require your loved one to see the doctor immediately**. Also, **be sure you know what to do if your loved one needs immediate medical attention**.

EMERGENCY AND PREPAREDNESS STRATEGIES

Here are some strategies that, if needed, can help you respond quickly and decisively:

- You should have easy access to your loved one's personal and medical information, and this information needs to be kept up-to-date.
- Keep emergency contacts in your cell phone contact list and keep a copy of these contacts in a place where others can easily find it.
- Keep an emergency medical ID card, as well as health insurance and Medicare identification cards, in your loved one's wallet or purse—and keep copies of these in yours.
- It could also be helpful to keep a card with emergency contacts listed.
- Know the location and quickest way to the nearest hospital emergency room.
- If you suspect the situation is life-threatening, call 9-1-1 immediately.
- If your loved one lives alone, consider a medical alert device. These devices are often wearable and normally include a button that alerts a central service and emergency staff when the wearer is having a medical emergency.

LEARN THE WARNING SIGNS

Here are symptoms that require your loved one to see the doctor **immediately**:

- Severe abdominal pain
- Chest pain or shortness of breath
- Seizures
- New onset of a fever or if the body temperature is much higher than usual
- Excess bruising or bleeding anywhere on the body
- Confusion or mood changes
- A combination of symptoms such as severe headache with neck stiffness and fever

FINDING A NEW DOCTOR

Building up a relationship with your loved one's doctor takes time and commitment. So, if your loved one's doctor retires, changes jobs, or otherwise becomes unavailable, it can leave both of you feeling vulnerable and insecure. Finding a new doctor can take time and effort, and it can be a complicated process.

FINDING A NEW HEALTHCARE PROVIDER

Follow these steps to help your loved one find a new doctor:

- STEP 1** Contact the Lupus Foundation of America, local hospitals, or a university medical center, or look online for names and locations of doctors who specialize in caring for people with lupus. These doctors are called rheumatologists.
- STEP 2** Contact doctors on your list for more information and find out about:
- Office hours and how the office responds to patient calls after hours.
 - Which hospital(s) the doctor is affiliated with.
 - The type of insurance accepted.
 - The payment policy for services.
 - The doctor's experience in treating people with lupus. Provide pertinent information about your loved one's health care needs to determine if the doctor is able to help.
- STEP 3** Evaluate how the office personnel responded to your questions. Were you put on hold for a long period of time, or more than once? Was the person that you talked with courteous and interested in answering your questions?
- STEP 4** Share information with your loved so he/she can choose a new doctor.
- STEP 5** Help your loved one schedule the first appointment. Ask if you can accompany him/her to meet the new doctor.
- STEP 6** If your loved one is not comfortable with the new doctor, that's OK! Keep looking. You will find one who fits what you are searching for.

LOSS OF HEALTH INSURANCE COVERAGE

If your loved one loses health insurance coverage, you may need to work with them to help them find coverage.

WHERE TO FIND COVERAGE

It is important to know where to turn for help:

- Those who lose health care coverage due to job loss may be able to maintain their coverage through COBRA (the Consolidated Omnibus Budget Reconciliation Act) (dol.gov). COBRA is a federal law that may allow individuals and their families to pay to keep their health insurance, usually for up to 18 months. This gives individuals time to find other options for health insurance coverage.
- See if your loved one is eligible for Medicare or Medicaid. Visit the Lupus Foundation of America's online insurance page for more information (lupus.org/resources).
- People who lose their health insurance can choose to buy coverage from the Health Insurance Marketplace (healthcare.gov). The Marketplace website will allow you to compare coverage plans based on cost, benefits, and other features that may meet certain individual needs. If a person needs to sign up outside of the open enrollment period, they may have several options.

PREPARING FOR FINANCIAL EMERGENCIES

Financial emergencies due to lupus can range from a limited, unexpected situation to a more permanent financial hardship. When planning, it is wise to set aside some emergency funds. Generally, an emergency fund should hold enough money to cover living expenses for at least three months, or more. However, a catastrophic event, such as serious complications due to chronic illness, can result in medical bills and other expenses that suddenly leave one financially overwhelmed.

PLANNING AHEAD

What can you do when faced with a financial emergency?

Evaluate

Evaluate the situation. What are the circumstances?

Investigate

Find out if your loved one has access to short- or long-term disability insurance.

Review

Review your loved one's budget and prioritize expenses. Are there any assets that can be turned into cash?

Seek help

Talk to lenders about negotiating a payment plan and to a bank representative about financial hardship options.

Contact the local Human Services Department for information about emergency funds.

Dial 2-1-1 for referrals to financial and community services (applicable in most states). Be specific about why your loved one needs immediate financial assistance.

Contact us

Contact the Lupus Foundation of America's Health Educators [here](#) or you may call 1-800-558-0121.

For more information and helpful resources, visit the National Resource Center for Lupus (www.resources.lupus.org).

FIVE IMPORTANT DOCUMENTS YOU SHOULD HAVE

There are several documents that will be needed, in case of an emergency. Keep this information confidential and in a safe location that you have access to.

TYPES OF DOCUMENTS

You, or someone else that your loved one chooses, should have access to:

- Bank names and locations, account numbers, and types of accounts.
- Insurance company policy names, numbers, and types of insurance.
- If applicable, Social Security and Medicare numbers.
- Government or military work history, including supporting documentation.
- Advance directives, durable power of attorney, and an up-to-date will, if available.

SECTION V

Caring for Children and Teens

Caring for children and teens with a chronic illness requires patience and an acceptance that certain lifestyle changes will have to be made. Additionally, you have the responsibility of making sure that family dynamics and routines move towards a new understanding of what “normal” is. Finally, whether your child is diagnosed with lupus as a child or as a teen, you have the responsibility of helping them transition into adulthood, armed with an understanding of how to manage the impact of lupus on their life. There’s a lot to think about and a lot to do, but the following four steps will help you stay on track.

TRACK YOUR CHILD'S HEALTH AND KEEP THEM INVOLVED AND ENGAGED

Learn as much as you can about the disease, so you can recognize how it is affecting your child. The Lupus Foundation of America's website has several sections and resources geared towards children and teens living with lupus (lupus.org/tag/children-teens).

HOW TO FOLLOW YOUR CHILD'S HEALTH:

Track and learn to recognize

Track and learn to recognize changes in your child's day-to-day health that may be a warning sign of a lupus flare. This is vital when creating a care plan for your child.

Create a daily care plan and start a care file

Create a daily care plan and start a care file to help you respond to your child's health needs and communicate with your child's health care team. You may want to add specific pages that are relevant to your child's school and other activities, such as important contact information and any specific health needs or reminders.

Talk to your child about their symptoms

Keep it simple and use age-appropriate language. Small children may not understand the nature of lupus, but most likely they are aware that something is wrong.

Involve your child

Involve your child in making healthy choices about care needs. This is a positive approach to accepting the illness, a little at a time. Make it fun and offer small rewards to acknowledge your child's participation in his/her care.

Encourage your child

Encourage your child to participate in planning visits to the doctor. Allow him/her to talk to the doctor, which can help decrease fear about the illness.

Establish a caregiving routine

Encouraging your child to participate in his/her care (as safe and appropriate) can provide a sense of security, control, and acceptance of lupus.

FIND A SHOULDER TO LEAN ON

To help you take care of your child in the best way possible, *you need to take care of yourself*. You can't do it all. Determine who you can turn to for support. Sometimes, it takes a community to help a family live as normal a life as possible in the face of chronic illness.

BUILDING A SUPPORT SYSTEM

How can you find support and encouragement for your ill child?

Stay in regular contact

Stay in regular contact with your child's health care team and talk to them about how your child is coping with the disease.

Explain the disease

Explain the disease to your child's teachers. Talk to them about any special needs and ask if you can help plan your child's schedule and schoolwork.

Inform the school nurse

Make sure the school nurse is aware of your child's illness, medications, and other essential health needs.

Talk with the school counselor

Talk with the school counselor about support and encouragement for your child.

Ask for help

Ask for help from friends and family members. Let them know what would be helpful to you and your child.

Encourage your child

Encourage your child to have normal relationships with peers. Reach out to other parents for social support.

Support groups can help

Support groups can help parents strengthen coping skills and reduce stress. If necessary, talk to a mental health professional who is familiar with issues surrounding chronic illness and children.

UNDERSTAND THE EMOTIONS CAUSED BY LUPUS AND HELP YOUR CHILDREN EXPRESS THEM

Sometimes, children are not able to express what they are feeling, so it may be up to you to help them understand and express their feelings appropriately. This is true for children with lupus as well as their siblings, who may also be having a hard time emotionally.

COMMUNICATION STRATEGIES

Ask your child or children how they are feeling

Help them to understand that there are no right or wrong feelings, and how to express their feelings in a healthy way.

Not talking about feelings may exaggerate anger, confusion, withdrawal, or fear

Sometimes, children may act out if they are not able to tell you what they are feeling. Ongoing negative behaviors or extreme withdrawal and isolation from the family should be discussed with the child's doctor.

Children need to know that the disease is not their fault

Just like adults, a better understanding of lupus will help them cope with their feelings about the disease.

Siblings can also feel angry, confused and fearful

They may be afraid that their brother or sister will die. Ask them how they are feeling and help them understand how the disease is affecting the child who is sick. They also need to know that they cannot catch lupus. Siblings need to know that they are equally important in the family. If it makes them feel good, encourage them to be a part of caregiving. Give them choices and reward their efforts.

Maintain normal family activities

Family fun, without focusing on the disease, is healthy and necessary.

HELPING TEENS TO TAKE CONTROL OF THEIR HEALTH

Teenage years are a time of transition from childhood to adulthood. Teens are developing a new identity that is already emotionally intense and demanding. Lupus can interfere with an adolescent's development of independence, peer relationships, and day-to-day normal activities. Adolescence is stressful for healthy teens; add the stress of living with a chronic illness and adolescence can be overwhelming. What can parents, as caregivers, do to help their teens learn to manage their health?

ENCOURAGE HEALTHY COMMUNICATION AND ACCEPTANCE OF FEELINGS

- Talk to your teen about how the disease is affecting him/her. Ask your teen what is most worrisome at this time.
- Encourage your teen to talk about feelings, whether it is with you, a friend, a school counselor, or other teens with lupus. Certain feelings, such as anger, sadness, anxiety, and fear of the unknown, are normal. Talking can provide a sense of relief and new perspectives on living with lupus.
- You can also encourage your teen to keep a private journal as a healthy outlet for their thoughts and emotions.
- Transitioning from diagnosis to a life with chronic illness will bring changes. Revisit expectations and routines with an open mind.
- Teens experiencing ongoing signs of depression may seem unable to adjust to long-term health issues. Talk to the teen's doctor to determine if symptoms are related to the physical effects of lupus, medications, or the stress of coping with the disease.
- Talk to the teen's doctor about treatment options, including seeing a mental health professional. Seeing a counselor provides teens the opportunity (and privacy) to talk about things that they are not ready to share with others.
- A professional can help teens develop appropriate coping skills to live with lupus now, and prepare for a healthy transition from adolescence to early adulthood.

ENCOURAGE INDEPENDENCE AND RESPONSIBILITY

Involve your teen in activities that promote independence and responsibility over their own health:

Encourage your teen to take responsibility

Encourage your teen to take responsibility for the management of their health. Involve him/her in determining a care plan and making healthy choices. If they own the plan, they will be more likely to adhere to it.

Be careful not to do too much for your teen

The more you do, the less your teen must learn to do, and this may end up hurting their physical and emotional health in the long run.

Be ready to take a step back

As your teen takes on more responsibility for their health, it will be important for the doctor--patient relationship to change as well. If your teen is interested in taking a more active role, be prepared to take a back seat at appointments, so they can carve out a new relationship with their doctor.

Build your teen's self-esteem

Help your teen to recognize strengths and build on them. Acknowledge their successes.

Staying involved in peer relationships and activities

Staying involved in peer relationships and activities is important to your teen. Living a life that is as normal as possible can add to your teen's sense of independence and will decrease their sense of "being different."

COPING WITH LUPUS

Stay on top of the practical aspects of coping with lupus, and encourage your teen to do so as well.

Stay involved with your teen

Are doctor's orders being followed? How is your teen doing in school?

Be aware of limitations caused by the disease

Be aware of limitations caused by the disease, including pain and fatigue, changes in appearance, and side effects of medications. For both of you, accepting this "new reality" takes time. Be patient.

Learn as much as you can about lupus

Learn as much as you can about lupus, but make sure your teen also takes on the responsibility of this knowledge. The more they understand what is happening to their bodies, the more empowered they will be to cope with the effects of lupus.

Keep them involved

As you communicate with insurance companies and various specialists, don't be afraid to let your teen learn about the paperwork and practical aspects of handling their health care. Keep them involved so they can manage these logistics confidently in the future.

Talk to your teen

When your teen turns 18, you may have to fill out and sign special forms to ensure that you can remain involved in the management of their health. Talk to your teen about how involved they want you to be, and speak with their doctor about any forms that need to be completed.

SECTION VI

Appendix: Forms

Care File

This file holds your loved one's personal information, current diagnosis and medical history, doctor and other health care provider contact information, doctor visit dates and changes in treatment, names of medications, dosages, and any special precautions, as well as emergency contacts. This file allows you and health care providers to provide proper care for your loved one and should be taken to all doctors' appointments. It is also a useful way to organize up-to-date information in one place.

Doctor Visit Tracker

Bring this form with you to fill out during each doctor visit. It is meant to help you keep track of which doctors your loved one is seeing, the purpose of each visit, questions asked during the visit and answers provided, the medical evaluation and outcome of each visit, and next steps regarding health care.

Medications

Use this form to keep track of the medications your loved one is using and information regarding medication dosage, frequency, and dates started and stopped. This will help you and health care providers stay organized regarding treatment decisions.

Daily Care Plan

This file will help you stay organized with the daily and long-term needs of your loved one. It is useful for those who share the caregiving duties when the primary caregiver is unavailable. It addresses information regarding medications, diet, and doctors' appointments.

**PRIMARY CAREGIVER
GENERAL INFORMATION**

NAME	D.O.B.	SEX M F
-------------	---------------	-------------------

RELATIONSHIP TO CARE RECIPIENT

HOME ADDRESS

CITY	STATE	ZIP CODE
-------------	--------------	-----------------

PHONE 1 (HOME)	PHONE 2 (CELL)
-----------------------	-----------------------

E-MAIL

EMPLOYER/PLACE OF WORK	WORK PHONE
-------------------------------	-------------------

WORK ADDRESS

CITY	STATE	ZIP CODE
-------------	--------------	-----------------

EMERGENCY CONTACT INFORMATION (IF NOT SAME AS ABOVE)

NAME

RELATIONSHIP TO CARE RECIPIENT

HOME ADDRESS

CITY	STATE	ZIP CODE
-------------	--------------	-----------------

PHONE	E-MAIL
--------------	---------------

NOTES

**CARE RECIPIENT
GENERAL INFORMATION**

NAME		D.O.B	
SOCIAL SECURITY NUMBER			SEX M F
HOME ADDRESS			
CITY	STATE	ZIP CODE	
PHONE 1 (HOME)		PHONE 2 (CELL)	
E-MAIL			
EMPLOYER/PLACE OF WORK			WORK PHONE
WORK ADDRESS			
CITY	STATE	ZIP CODE	

INSURANCE INFORMATION

MEDICAL INSURANCE CARRIER	
SUBSCRIBER'S NAME	SUBSCRIBER'S SSN
GROUP NUMBER	
POLICY NUMBER	
RELATIONSHIP TO SUBSCRIBER	
DENTAL INSURANCE	
SUBSCRIBER'S NAME	SUBSCRIBER'S SSN
GROUP NUMBER	
POLICY NUMBER	
RELATIONSHIP TO SUBSCRIBER	

HEALTH CONDITION INFORMATION

DIAGNOSIS (Type of lupus)

DIAGNOSED BY

DATE OF DIAGNOSIS

SYMPTOMS

ALLERGIES

NOTES

PHYSICIAN INFORMATION

PRIMARY CARE PHYSICIAN

ADDRESS

CITY

STATE

ZIP CODE

PHONE

FAX

WEBSITE

E-MAIL

RHEUMATOLOGIST

ADDRESS

CITY

STATE

ZIP CODE

PHONE

FAX

WEBSITE

E-MAIL

DERMATOLOGIST

ADDRESS

CITY

STATE

ZIP CODE

PHONE

FAX

WEBSITE

E-MAIL

OTHER SPECIALIST:

ADDRESS

CITY

STATE

ZIP CODE

PHONE

FAX

WEBSITE

E-MAIL

PHYSICIAN INFORMATION (cont.)

OTHER SPECIALIST:

ADDRESS

CITY

STATE

ZIP CODE

PHONE

FAX

WEBSITE

E-MAIL

OTHER SPECIALIST:

ADDRESS

CITY

STATE

ZIP CODE

PHONE

FAX

WEBSITE

E-MAIL

OTHER SPECIALIST:

ADDRESS

CITY

STATE

ZIP CODE

PHONE

FAX

WEBSITE

E-MAIL

OTHER SPECIALIST:

ADDRESS

CITY

STATE

ZIP CODE

PHONE

FAX

WEBSITE

E-MAIL

PHARMACY INFORMATION

ADDRESS		
CITY	STATE	ZIP CODE
PHONE	FAX	
WEBSITE		
E-MAIL		

HOSPITAL INFORMATION

ADDRESS		
CITY	STATE	ZIP CODE
PHONE	FAX	
WEBSITE		
E-MAIL		

DOCTOR/HEALTH CARE VISIT

DOCTOR/SPECIALIST NAME

TYPE OF DOCTOR

DATE OF VISIT

TIME

PURPOSE OF VISIT/QUESTIONS FOR DOCTOR

MEDICAL EVALUATION AND OUTCOME

NEXT STEPS IN HEALTH CARE

NOTES/OTHER

CAREGIVER DAILY CARE PLAN

CAREGIVER NAME _____

DATE _____

MEDICATION(S) ADMINISTERED

NAME OF MEDICATION	TIME ADMINISTERED	NOTES (Allergic reactions, etc.)

DIET AND NUTRITION

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

DOCTOR APPOINTMENT

DOCTOR NAME	REASON FOR VISIT	NOTES

NOTES (i.e. planning for the week/events, important information, etc.)
