Create and Strengthen Your Social Support Network
Whether you have lupus or are a caregiver to someone with lupus, a strong support network is critical to maintaining optimal health and keeping the normal stresses of life in check.
Just as it takes a medical team to manage lupus, living well with lupus requires a team of people who offer support—emotional, physical, and spiritual.
Learn more about the benefits of social support and **how to build and grow your network**. Once your network is in place, you’ll find it to be invaluable day to day and through the years.
SEVEN STEPS TO BUILDING YOUR NETWORK

1. Know the dangers of isolation
2. Reach out
3. Set up several types of support
4. Ask
5. Connect
6. Share
7. Volunteer
Know the dangers of isolation

STEP ONE

It’s easy to be overwhelmed when you’re managing a chronic disease like lupus, or when caring for someone else. This is when it’s most important to reach out to your support network. The dangers of isolation may start small, but a lack of interaction with others can negatively affect your health and well-being over time.
Spending time alone is not the same as being isolated. Alone time is sometimes a good thing. Being isolated, however, is not.

“People who have more social support tend to fare better both physically and emotionally. It’s important for people to express that they have been feeling really lonely or unsupported.”

— Francine Rosenberg, Psy.D.
MORRIS PSYCHOLOGICAL GROUP
PARSIPPANY, NEW JERSEY
A chronic illness like lupus can be isolating for many reasons.

FOR EXAMPLE, YOU CAN BECOME ISOLATED IF:

- You don’t know anyone else who has the disease.
- You don’t understand the disease.
- You have always been healthy until lupus developed.
- You cannot keep up with the social life you used to enjoy.
- You have to stop working or drop out of school for a time.
- You have no close family members or friends to give you support.
Being assured that you are a valuable member of society and that you matter to the people in your life will help you to feel more secure. Using daily positive affirmations can help, too.
One of the affirmations people with chronic illnesses often state is:

“I have this disease, but it doesn’t have me.”
Research shows that getting the help you need (known as “perceived social support”) improves your quality of life, whether you have lupus or you’re a caregiver. A strong support team will have people who can help in different ways. It’s not necessary, or likely, that everyone in your support network can meet all of your needs. The important thing is that you can count on these people when you need them.
The individuals who make up your support network can include:
Family members

A diagnosis of lupus affects the whole family. You may find that cousins, aunts, uncles, siblings, and your spouse will empathize and naturally step into the role of supporter.

Neighbors

People in your neighborhood often can provide a home-cooked meal during a stressful time, or they can simply be a nearby source of comfort.

Co-workers

The people you work with can help by being empathetic about your situation. You may need to telecommute, take a leave of absence, or use flex time, which will require the cooperation and support of your colleagues.
Medical team

If you’re a caregiver, your loved one’s providers and office staff, social workers, and other professionals will probably understand what you are going through and can be supportive of your caregiving role.

Lupus support group members

People in this network have knowledge about lupus and can offer strategies and suggestions based on their experience.
Teachers and school instructors

When you are caring for a child with lupus, keep his or her teachers informed and let them know how they can help.

Therapist or counselor

It’s important that you have an outlet for your emotions. Check to see if mental health services are included in your employer’s health coverage. If not, look for free services in your community.
STEP THREE

Set up several types of support

“The first part of putting together your support network is really identifying what you need,” says Dr. Rosenberg. “Define what you think will fill that void, and explore all the different opportunities that may be available.”
Know the types of support to rely on:
Emotional support

Life with lupus can be emotionally challenging. Having people to help you talk through problems or support you through rough spells is essential. The people you rely on for emotional support should:

- Listen to you.
- Believe you and believe in you, and care about you unconditionally and nonjudgmentally.
- Help you stay strong in the face of an incurable, invisible illness, or as you help a loved one facing health challenges.
- Be there for you in an emergency.
“As much as possible, families should talk to each other about how they’re feeling. It’s OK to be frustrated. It’s OK to be annoyed. It’s part of life with lupus.”

— Eliza F. Chakravarty, M.D., M.S.

ARTHritis and CLINICAL IMMUNOLOGY ASSOCIate MEMBER, OKLAHOMA MEDICAL RESEARCH FOUNDATION IN OKLAHOMA CITY
Physical and mental wellness

Physical activity benefits the body and mind. But it’s also important not to overdo exercise. Experts can assist you in finding the right balance and advise you on what types of activities are safe and beneficial, given your abilities. In addition to the medical team that manages lupus, seek out people who can:

- Provide expertise in physical health (physical therapists, fitness instructors).
- Provide expertise in mental wellness health (massage therapists, yoga or tai chi instructors, psychotherapists).
Task-related support

Your social support team can pitch in to tackle basic tasks of daily life that you may find difficult because you are feeling fatigued or overwhelmed. People on your team could:

- Serve as an advocate (at doctor’s appointments, with the insurance company).
- Help with daily chores (dog walking, prescription pickups, organizing fun activities).
- Lend a hand at work (contribute hours to a sick leave bank, share job duties, fill in during an emergency, commute by ride-sharing).
- Give financial guidance (an accountant or a financial adviser).
Support groups

Dr. Rosenberg advocates seeking social support through an in-person group model. Such groups help people see that others have the same problems. Support group members can:

- Suggest new ways of coping with problems.
- Help you feel less isolated.
- Discuss the issues you face openly and without judgment.
The biggest benefit of getting involved in a lupus support group is that **you’re all there for a common reason.** Everybody has experienced something similar and can understand what you are going through, and that in turn helps you feel less alone.”

— Francine Rosenberg, Psy.D.

MORRIS PSYCHOLOGICAL GROUP

PARSIPPANY, NEW JERSEY
Family support

Managing your own or a loved one’s lupus while also taking care of a family can pile on stress. Your support team can help keep family life on track. Look to your team to perform these tasks:

- Assist with child care (rides to and from school, baby-sitting, car pools to extracurricular activities).
- Help with meal preparation (grocery shopping or preparing frozen portions for later use).
Spiritual support

Spiritual support can help buffer some of the stress and negativity that arises from living with lupus and from caregiving, and it can bring a greater sense of meaning to one’s life. Members of your spiritual support team can provide:

- Guidance through prayer and religious services.
- Instruction in meditation, guided imagery, or deep breathing exercises.
- Self-help strategies via books, webinars, or support groups.
STEP FOUR

Ask

By asking for help, it may feel like you are giving up your independence. But most people want to help. Although they may not completely understand what you’re going through, they want to be supportive. It is important to understand how to make your needs known to people who can assist you. Learning to ask for help, and learning to accept help that is offered, will get easier over time.
Not everybody has the skills to seek out support, especially if you’re a little socially shy. If it feels awkward to make a request, it may require practice initiating certain conversations.”

— Francine Rosenberg, Psy.D.
MORRIS PSYCHOLOGICAL GROUP
PARSIPPANY, NEW JERSEY
Knowing what you need help with, and having a list of people you think would be good matches for those roles, will make each “ask” much easier. Next to people’s names, put their strengths: what they like to do and what they do well.
Tap into people’s skills.

For example, if your co-worker is a whiz at finding bargains, ask her to help you with your holiday gift list. Give her some gift ideas and a budget for each person, and make sure it’s OK to reimburse her later.
Be specific with your request.

Does your best friend love to cook? She may be thrilled to try out some new recipes on you! Being specific is more effective. Say, “Would you be able to make a casserole for our family supper this Friday?” instead of, “Could you cook something for me sometime?”
Try arranging a barter exchange.

Perhaps you can baby-sit for a family member in exchange for help with insurance paperwork, or organize closets in exchange for yardwork.

Think creatively!
STEP FIVE

Connect

Staying connected socially can help you put lupus into perspective. The goal is to make sure lupus is only one part of your life, not your whole life. Along with hobbies you enjoy, choose some activities that bring you into contact with other people.
When you connect with others, you’re thinking and talking about something that’s not your health. I’m not saying to completely ignore that, but we don’t want it to consume your whole life. **We want you to think of yourself as a person who happens to have lupus, rather than that your whole existence is as a lupus patient.**”

— Eliza F. Chakravarty, M.D., M.S.
ARTHRITIS AND CLINICAL IMMUNOLOGY ASSOCIATE MEMBER, OKLAHOMA MEDICAL RESEARCH FOUNDATION IN OKLAHOMA CITY
Get Connected Online with LupusConnect
LupusConnect is a new online community launched by the Lupus Foundation of America that provides people with lupus and their loved ones a safe and understanding space to share experiences, find emotional support, and discuss ways to manage the disease. Start connecting at LupusConnect.Inspire.com.
No matter how isolated lupus can make people feel, LupusConnect offers people the opportunity to express their fears, frustrations, and hopes with others who understand lupus firsthand.”

— Sandra C. Raymond
LUPUS FOUNDATION OF AMERICA CEO
**STEP SIX**

**Share**

You’ll probably find that you share different aspects of what you’re going through with different people. That’s why it’s so helpful to have a variety of people to talk with and places where you can speak and be heard.
People’s emotions are very complicated when they’re dealing with chronic illness. Regular meetings with an objective person, such as a trained counselor or therapist, can be very helpful. You may also want to engage with people who understand lupus and know what you’re going through.
What I recommend is that, over time with any given relationship within your support system, you gradually increase the amount that you share.”

— Eliza F. Chakravarty, M.D., M.S.
ARTHRITIS AND CLINICAL IMMUNOLOGY ASSOCIATE MEMBER, OKLAHOMA MEDICAL RESEARCH FOUNDATION IN OKLAHOMA CITY
Volunteerism offers social support benefits, because helping others can make you feel better about life in general. One good option is volunteering for a Lupus Foundation of America chapter or a support group.
Think about the social causes you are passionate about and the skills you have to offer. Check out an organization’s website for volunteer opportunities, or call the local office and ask how you can help.

“There is research to support that helping others who have a similar problem that you have is very validating.”

— Francine Rosenberg, Psy.D.
MORRIS PSYCHOLOGICAL GROUP
PARSIPPANY, NEW JERSEY
Above all, remember:
A strong social support network will help you to stay connected—with family, with friends, with community.