

*RESOURCES AND TOOLS  
FOR  
LIVING WELL WITH LUPUS*



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# WHAT IS LUPUS?

An estimated 1.4 million Americans, most of them women, suffer from lupus, a chronic auto-immune disease in which the immune system attacks the body. With symptoms ranging from skin rashes to kidney dysfunction, lupus is a complicated and frustrating disease, the cause of which is still unknown.



# 3 TYPES OF LUPUS

## Systemic Lupus Erythematosus

Systemic lupus is the most common form of lupus, and is what most people mean when they refer to "lupus." Systemic lupus can be mild or severe. Some of the more serious complications involving major organ systems are:

## Cutaneous Lupus Erythematosus

Cutaneous refers to the skin, and this form of lupus is limited to the skin. Although there are many types of rashes and lesions (sores) caused by cutaneous lupus, the most common rash is raised, scaly and red, but not itchy. It is commonly known as a discoid rash, because the areas of rash are shaped like disks, or circles.

## Medication Induced Lupus

# FIGHTING LUPUS MIND, BODY & SPIRIT

## RULES OF ENGAGEMENT:

- Pace yourself, and know your limits.
- Communicate your needs to those who care for you.
- Practice patience to help get through trying times.
- Plan and organize your medical records and doctors' visits.
- Prioritize your responsibilities in life and do not over commit yourself.
- Cultivate a sense of humor to help you through tough times.

REMEMBER KNOWLEDGE IS POWER!

# SELF-MANAGEMENT SKILLS FOR LUPUS

- Communication
- Coping Strategies and Stress Reduction
- Physical Activity and Exercise
- Managing Medications
- Nutrition
- Mental Health

# COMMUNICATION

Effective communication involves more than one person.

- Be clear and concise.
- Use "I" messages. "I feel.."
- Acknowledge the other person and his/her message.
- If clarification is needed, ask the person to rephrase what was said or rephrase what the person said.
- Non-verbal communication sends an important message.

A patient should learn to communicate effectively with members of the health care team.

The patient needs to get her message across to the health care professional in the limited time available.

# STRESS MANAGEMENT TECHNIQUES:

Stress Management Techniques include:

- Meditation
- Muscle Relaxation
- Guided Imagery
- Writing in a Journal, Reading, Coloring
- Talking with a trusted friend or family member
- Joining a Support Group
- Talking with a professional such as a Social Worker, Psychologist, or Counselor.

# PHYSICAL ACTIVITY

**Physical activity** and **Exercise** are important in the self-management of Lupus for two reasons: Physical activity improves both general health and physical fitness.

Health professionals emphasize physical activity four or more days a week. The activity should be of moderate intensity and the amount of **Exercise** can be accumulated throughout the day to total 30 minutes.

- Walking
- Cleaning
- Dancing
- Thai Chi
- Yoga
- Gentle Stretching



# LIVING A LIFE OF WELLNESS

**Wellness** can be defined as a “...active process of becoming aware of and making choices toward a healthy and fulfilling life,”

Yoga Breathing  
Restorative Yoga  
Low-Impact Exercise for Joints  
Meditation  
Eating a Healthy Diet  
Laughter

These are all examples of types of Wellness.  
Exercise, Stress Management, and Nutrition are three big pieces of the Wellness picture.

# Managing Medications

Managing medications is an important self-management skill. Some tips for patients to manage them sensibly include:

Know about the medication(s) you are taking: name of the drug, reason for taking it, what it is supposed to do, dosage, time(s) of day to take it, how to take it (with food or on an empty stomach), any possible side effects.

Do not let your medications run out !!!

When a new medication is prescribed ask the pharmacist if you have any questions.

# NUTRITION AND HEALTHY EATING

It is especially important for a person with a chronic illness like lupus to eat a balanced diet. If your insurance will cover it schedule an appointment with a nutritionist to help plan a diet for your specific needs.

Bad eating habits can make it harder for your body to fight lupus. Luckily, simple changes in what you eat can make a big difference in how you feel day to day and protect your body—especially your heart—from lupus damage. The first step to healthy eating:

Cut back on the Bad and Eat More of the Good.

The Bad – Fat, Caffeine, Salt, Alcohol

The Good - Fruits & Vegetables, Calcium & Vitamin D, Whole Grains & Wheat, Low-Fat Proteins: (fish, chicken and beans) Water: Drink at least 8 cups of water a day

# BENEFITS OF SELF-MANAGEMENT

The person feels more in control of his/her situation .

The person feels valued as an active participant in his/her health care.

Physical activity promotes general health, decreases pain and stiffness.

Decreases feelings of depression as well as improves mood and sleep.

Exercise improves daily energy level.

Decreased reports of pain, increased functional abilities and a reduced number of hospitalizations and physician visits.

# PERSONAL RESPONSIBILITY

## SELF CARE

Self care is taking responsibility for your own personal health maintenance. People need to be more conscious about their health and want to have the most important role in taking care of themselves. Self care includes all health decisions people make for themselves and their families. Self care is exercising to maintain physical fitness, eating well for your body, and good mental health. It is also avoiding health hazards.

## SELF ADVOCACY

People with disabilities need to take control of their own lives. That includes being in charge of their own personal care in health and all societal systems. Self advocacy is about people speaking up for themselves. It means that although a person (with a disability) may call upon the support of others, the individual is entitled to be in control of their own resources and how they are directed. It is about having and knowing your right to make life decisions not controlled by others.

## SELF WELLNESS

Self wellness is the quality or state of ones being. Living healthy in the body and the mind, which is the result of the person's direct effort. Self wellness is taking a personal approach to healthcare that focuses on preventing illness and prolonging life, as opposed to just treating disease and illness.

EXERCISE

MEDITATE

EAT WELL

PRAY

WALK

BREATHE

REMEMBER ONE DAY AT A TIME AND TOMORROW CAN BE BETTER IF YOU TRY

# Developing Effective Coping Skills

Many people with Lupus go through phases in which they feel a sense of powerlessness not only during flares but also during periods of recuperation and remission.

**First:** for the patient to submit to the disease, accept Lupus, and a lifestyle of illness as his or her identity.

**Second:** for patients to create a new identity based on reworked, realistic goals and expectations. This gives a sense of greater control, an improved self-image, and a positive and hopeful attitude. This option requires imagination, resilience, and determination.

**Third:** Lupus patients need to accurately assess their pain and fatigue levels and understand how changes in these levels will affect their ability to work, play, and carry out activities of daily living.

# EFFECTIVE COPING SKILLS FOR LUPUS

- Talk with your doctor
- Get plenty of rest
- Make lists
- Use a planner
- Keep stress levels low
- Try to accomplish one task at a time
- Be **Mindful** about your memory
- Be **Kind** and **Compassionate** to yourself

# WHEN LIVING WITH LUPUS REMEMBER:

STAY PHYSICALLY FIT

BE ACTIVE

STAY MOTIVATED

LEARN TO COPE WITH GRIEF

LAUGH

PRACTICE GRATITUDE

ALWAYS REMEMBER LUPUS DOES NOT DEFINE YOU!





# QUESTIONS AND ANSWERS