



# **Living with Lupus: Learn from the Experts**

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# Overview

- **Living with lupus**
  - Knowing as much as you can about this complex disease
  - Understanding how lupus can affect your body
  - Making lifestyle changes to stay as healthy as possible
- **Successfully managing lupus starts with awareness**
  - Managing flares, changes in symptoms, physical conditions
  - Coping strategies

# Topics

- **Lupus Clinical Features and Prognosis**
- **Treatment Considerations**
- **Lifestyle Considerations**
- **Coping Strategies**
- **Workplace and Resources**
- **LFA Resources**

# Clinical Features

- **Lupus is a chronic autoimmune disease that can affect virtually any part of the body.**
- **Lupus is much more common in women than in men. It can occur at any age.**
- **Lupus is a disease of spontaneous flares and remissions.**
- **The most common symptoms are fatigue, photosensitive rash, and joint pains.**

# Prognosis

- **Most people with lupus can look forward to a normal lifespan:**
  - Follow physician instructions
  - Know when to seek help for side effects or new symptoms
- **Serious problems occur in some people and generally can be treated successfully**
  - Close monitoring is essential
  - Take medications as prescribed

# Treatment Considerations

- **For most people proper treatment can**
  - Reduce symptoms
  - Protect against serious organ damage
- **Medications are an important part of managing lupus**
  - Lupus is different for each person
  - Physician looks for the best combination of medications for you

# Treatment of Mild-Moderate Lupus

- Rest
- Avoid sun exposure
- Topical corticosteroids
- Antimalarial drugs (plaquenil)
- Anti-inflammatory drugs
- Low-dose corticosteroids (prednisone)
- Health maintenance - preventative measures

# Treatment of Severe Lupus

- Often requires potent immunosuppressive drugs
- Close monitoring required for disease flares and/or medication side effects
- Consider participation in clinical trials



# **Lifestyle Considerations Overview**

- **Fatigue**
- **Rest**
- **Exercise**
- **Diet and nutrition**
- **Smoking**
- **Sensitivity to light**

# Fatigue

- **80% of people with lupus experience significant fatigue**
- **It is unclear why fatigue occurs in so many people with lupus, but many factors appear to play a role**
  - Disease activity
  - Pain
  - Medications
  - Poor physical conditioning
  - Mental health/Depression
  - Lack of social support

# Rest

- **Proper amounts of rest**
  - Extremely important for people with lupus
  - At least 7 hours of sleep per night is a good goal
  - Helps with fatigue
  - Helps when experiencing flares
- **Napping is helpful and sometimes necessary**
  - Allow extra time in your day to rest

# Exercise

- Like everyone else, people with lupus should exercise regularly
- Exercise plans should be discussed with your physician
- Low impact activities are best if you're experiencing swollen joints or muscle pain
  - Walking
  - Swimming
  - Bicycling
  - Yoga/Pilates
  - Stretching

# Exercise

- **Regular exercise and even simple low-impact movement will:**
  - Reduce or minimize stress
  - Help keep your heart healthy
  - Improve muscle strength and reduce muscle stiffness
  - Increase your range of motion
  - Help prevent osteoporosis

# Diet and Nutrition

- **There is no special diet for people with lupus**
- **A nutritious, well-balanced diet is advised**
  - Fruits, vegetables, whole grains and moderate amounts of poultry and fish
- **Avoid alfalfa sprouts, which may trigger flares**
- **Herbs, supplements and vitamins should be discussed with your physician**

# Diet and Nutrition

- **Alcohol can be used in moderation, but may complicate the use of some medications**
  - e.g., NSAIDs, anticoagulants, methotrexate
- **Corticosteroids may elevate blood pressure and cholesterol – so fat and salt should be limited**
- **Due to the increased risk of osteoporosis, it may be helpful to eat foods rich in calcium**
  - Green leafy vegetables, milk, cheese, yogurt, calcium supplements
- **If fluid retention is a problem, salt should be limited**

# Smoking

- Tobacco is especially harmful to people with lupus
- Smoking impairs the body's entire circulatory system and increases the risk of atherosclerosis, a condition seen often in lupus patients
- Flares in cutaneous lupus have been linked to an ingredient in tobacco
  - Stop smoking and avoid second-hand smoke



# Sensitivity to Light

- **Two-thirds of people with lupus have increased sensitivity to ultraviolet (UV) rays**
  - Sunlight, artificial light, or both
- **Excessive exposure to the sun can cause a lupus flare**
- **Use sunscreen when outdoors**
  - Both UVA and UVB protection
  - At least 30 SPF

# Sensitivity to Light

- Avoid sunlight between the hours of 10 am and 4 pm
- Clothing and hats also help protect from UV light
- For indoor light exposure, there are shields that cover fluorescent bulbs (can be ordered from several manufacturers)
  - Shields with nanometer readings of 380 to 400 are best

# Coping Strategies

- **Control fatigue:**
  - Learn to pace activities and listen to your body
- **Control stress:**
  - Identify your stressors and use methods to control the stress
  - Say “no” when necessary
- **Manage depression:**
  - Most episodes subside on their own; inform your doctor if your depression is prolonged

# Coping Strategies

- **Manage anger:**
  - Don't let anger bottle up
  - Communicate with family/friends and help them understand what you are feeling
- **Resolve guilt:**
  - Modify thoughts and behavior
- **Address intimacy issues:**
  - Pain, fatigue, depression and certain medications can lower your interest in intimacy
  - Good communication helps counter negative self perceptions

# Workplace Considerations

- **Address workplace issues**
  - Discuss needs with employer
- **Modify workstation if necessary to relieve physical stress factors**
- **Take on less physically demanding tasks**
  - Say “no” when necessary

# Workplace Resources

- **The Americans with Disabilities Act (ADA) — a valuable resource**
  - Employers cannot discriminate against individuals with a disability (chronic disease is a disability)
- **Employers may have short- or long-term disability benefits**
- **Social Security Administration (SSA)**
  - Primary source for financial assistance for persons who cannot continue to work

# Remember...

- **There is more to you as an individual than having lupus**
- **Allow for personal time**
- **Adhere to medication regimes**
- **Communicate**
  - It's okay to say no
  - Be open with loved ones and with your physician(s) and other health care providers

## **Also Remember....**

- **Continue to learn as much as you can**
- **Incorporate lifestyle changes**
- **Manage lupus with awareness**
  - Symptoms
  - Flares
  - Tension and stress
- **Use coping strategies identified here**



# On the Horizon

- There has been enormous progress in recent years in understanding the biology of lupus.
- Numerous new approaches to treatment are under development and/or investigation.
- Information on participating in clinical trials can be found on the LFA web site at:  
<http://www.lupus.org/clinicaltrials>
- **ACCESS** Trial for treatment of active lupus nephritis – see: <http://www.lupusnephritis.org>

# LFA National Office Resources

- Visit the LFA at [www.lupus.org](http://www.lupus.org)
  - LFA Nurse Health Educator available to answer questions by email or phone
  - Online resources and print materials
  - Find a local chapter and support group
    - Chapters and support groups can also help you find local community health resources
  - Ways to get involved (Walks, Advocacy, Facebook, Twitter, etc.)