



Lupus

A Patient Care Guide for Nurses
and Other Health Professionals

3rd Edition



Department of Health and Human Services

National Institutes of Health

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Musculoskeletal and Skin Diseases

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National Institute of Arthritis and Musculoskeletal and Skin Diseases
National Institutes of Health
1 AMS Circle
Bethesda, MD 20892-3675

Phone: 301-495-4484 or 877-22-NIAMS (226-4267) (free of charge)

Fax: 301-718-6366

TTY: 301-565-2966

E-mail: NIAMSInfo@mail.nih.gov

Lupus: A Patient Care Guide for Nurses and Other Health Professionals is intended to provide an overview of lupus and how to care for patients who have the disease. It is not intended to provide medical guidelines for diagnosing and treating lupus, nor is it intended to be all-inclusive. Specific medical advice is not provided, and NIAMS urges readers to consult with a qualified physician for diagnosis and for answers to individual questions.

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National Institutes of Health

National Institute of Arthritis and Musculoskeletal and Skin Diseases

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Credits

Original Author:

Terri Nass, RN
Wauwatosa, WI

Editors:

Julia Freeman, PhD
National Institute of Arthritis and
Musculoskeletal and Skin Diseases
Bethesda, MD

Anne Brown Rodgers
Cygnus Corporation
Rockville, MD

Contributors:

Carolyn M. Albright, MS, RN
Hagerstown Junior College
Hagerstown, MD

Roberta Horton, MSW, ACSW
Hospital for Special Surgery
New York, NY

Carolyn H. McGrory, MS, RN
Division of Rheumatology
Thomas Jefferson University
Philadelphia, PA

Phyllis Payne, MPH
Johnson, Bassin, & Shaw, Inc.
Silver Spring, MD

Anne Brown Rodgers
Cygnus Corporation
Rockville, MD

Ann Taubenheim, MS, RN
Cygnus Corporation
Rockville, MD

Reviewers:

Melanie C. Bacon, MPH, RN
George Washington University
Medical Center
Washington, DC

Marianna Crane, RN
National Institute of Arthritis and
Musculoskeletal and Skin Diseases
Bethesda, MD

Frances Talska Fischbach, RN, MSN
(Retired)
University of Wisconsin-Milwaukee
Milwaukee, WI

Frances Ingenito, RNP
Multipurpose Arthritis and
Musculoskeletal Diseases Center
University of Connecticut
Farmington, CT

John H. Klippel, MD
Arthritis Foundation
Atlanta, GA

Laura Robbins, DSW
Hospital for Special Surgery
New York, NY

Naomi Rothfield, MD
Multipurpose Arthritis and
Musculoskeletal Diseases Center
University of Connecticut
Farmington, CT

Robert A.S. Roubey, MD
Thurston Arthritis Research Center
Division of Rheumatology and
Immunology
University of North Carolina at
Chapel Hill
Chapel Hill, NC

Peter H. Schur, MD
Department of Medicine, Division of
Rheumatology
Brigham and Women's Hospital
Boston, MD

Susan Urrows, MS, RNP
Multipurpose Arthritis and
Musculoskeletal Diseases Center
University of Connecticut
Farmington, CT

John Winfield, MD
Thurston Arthritis Research Center
Division of Rheumatology and Immunology
University of North Carolina at Chapel Hill
Chapel Hill, NC

Cheryl Yarboro, RN
National Institute of Arthritis and
Musculoskeletal and Skin Diseases
Bethesda, MD

Graphic Designer:

Lindi R. Copeland
Circle Solutions, Inc.
McLean, VA

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Lupus erythematosus is a complex and challenging disease that affects the lives of many thousands of individuals and their families. With physical, emotional, and psychosocial aspects, this disease requires multidimensional and patient-centered treatment and support strategies. This comprehensive guide brings together information on a wide variety of issues that health professionals need to know about in order to provide these treatment and support strategies for their patients with lupus. The guide covers general background on lupus, new advances in research, laboratory tests used to diagnose and evaluate lupus, care of the lupus patient, medications used to treat lupus, psychosocial aspects of lupus, and patient education and information.

A key element of the guide is that it contains information useful to the whole patient care team: nurses, physicians, physical and occupational therapists, social workers, and patients themselves.

Many people worked on this revision to incorporate the immense knowledge obtained over recent years on lupus and its management and to create a reader-friendly and useful book. We wish to

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We hope that nurses and other health professionals across the country will find this new guide informative and useful as they work with people with lupus and their families.

Introduction

Lupus erythematosus is a unique, complex disease with a wide scope of symptoms. It is also an elusive condition in that it affects individuals differently and often does not follow a predictable course. For example, a patient who appears to be in remission during a routine office visit can present at an emergency room the following week with severe pericarditis or sudden stroke.

A person diagnosed with lupus may have symptoms and disease activity that are easily managed with treatment, but it is not uncommon for health care professionals to encounter a lupus patient with numerous severe symptoms that are difficult to control. No two lupus cases are alike. As a result, care of the patient with lupus erythematosus is a challenge that draws on all the resources, knowledge, and strengths the health care team has to offer. Each member of the health care team – physician, nurse, therapist, dietitian, social worker, among others – has an important role to play in treating specific aspects of the disease and in supporting the patient to cope with his or her condition.

Lupus: A Patient Care Guide for Nurses and Other Health Professionals provides an overview of lupus erythematosus and the elements involved in caring for patients with this disease. It focuses on systemic lupus erythematosus (SLE). The Lupus Guide is intended primarily for nurses and other health professionals who work on an ongoing basis with lupus patients. The guide also presents the tools these professionals need to

provide the best care possible for this important group of patients. Many of these patients will be cared for in an outpatient setting, but the Lupus Guide also addresses the needs of hospitalized patients.

Each chapter of the Lupus Guide deals with a specific aspect of the disease. Chapter 1, *Lupus Erythematosus*, provides a general overview of the disease, including brief discussions of the diagnosis, treatment, medications, and psychosocial aspects.

The chapter closes with a discussion of how these issues affect the way nurses and other health professionals provide care to lupus patients.

Chapter 2, *Advances in Lupus Research*, summarizes the current understanding of the etiology of lupus and describes areas of ongoing research. Recent research advances have significantly increased the understanding of lupus, and, as current research efforts unfold, there is hope for new treatments, improvements in patients' quality of life, and perhaps prevention of or cure for the disease.

Chapter 3, *Laboratory Tests Used to Diagnose and Evaluate SLE*, summarizes the main laboratory tests used to diagnose lupus and to monitor a patient's condition. These assessments include blood tests, measurements of autoimmunity, and tests for kidney disease.

Chapter 4, *Care of the Lupus Patient*, gives a system-by-system overview of the most common lupus manifestations and suggests nursing interventions. Several other key issues are also discussed, including general manifestations,

pregnancy, infection, and nutrition. Not every patient will experience all of the problems and symptoms described. However, it is important for health professionals to be familiar with the range of possible manifestations so that they can accurately assess their patients and develop sound treatment and care plans.

Chapter 5, *Medications Used to Treat Lupus*, covers the major categories of drugs currently used to control lupus symptoms: nonsteroidal anti-inflammatory drugs, antimalarials, corticosteroids, immunosuppressives, and intravenous immunoglobulins. These medications can often be used successfully to treat lupus symptoms, but their potential side effects can present other problems. Chapter 5 discusses each category of medication, describes its mechanism of action and use in treating lupus, and reviews the potential side effects associated with it.

Chapter 6, *Psychosocial Aspects of Lupus*, provides information on this critically important aspect of the disease. Because of the chronic, unpredictable, and evolving nature of lupus, patients often have to cope with serious emotional and psychosocial issues along with the physical dimensions of their illness. A good understanding of these issues will help nurses and other health professionals provide the empathetic and supportive care lupus patients need.

Chapter 7, *Patient Information*, contains 20 short fact sheets covering a broad range of issues related to lupus. Nine of the fact sheets deal with lupus medications. These Patient

Information Sheets are designed to help patients understand their disease and its symptoms and complications and to develop effective ways of living with and controlling lupus. Nurses and other health professionals will find the sheets helpful in their ongoing teaching efforts.

The Lupus Guide closes with a chapter of resources for further information on lupus, and an updated bibliography of the source materials used to develop the book.

Today, the prognosis for people with lupus is far brighter than it was 25 years ago. Advances in research, improved treatments, a growing list of support networks and information resources, and an increased emphasis on close cooperation between the patient and the health care team mean that, for many patients, it is possible to have lupus yet remain active and involved with life, family, and work. The Lupus Guide is intended to provide nurses and other health professionals with a solid grounding in this important disease so that they can provide the care to make an active and involved life a reality for women and men with lupus.

Chapter 1

Lupus Erythematosus



The challenge of caring for a patient with lupus erythematosus draws on all the resources, knowledge, and strengths the health care team has to offer. Because of the unpredictable, highly individualized, and frequently changing nature of the disease as well as the intricacy of each patient's needs, it is impossible to predict the outcome of treatment for one patient from the outcome of treatment for another. Careful listening to the person's concerns; a cooperative, multidisciplinary approach; and a flexible plan of care will provide the patient with consistent, supportive care and the reassurance that her or his needs are being met.



Definition and Description

Lupus means “wolf.”
Erythematosus means “redness.”

In 1851, doctors coined this name for the disease because they thought the facial rash that frequently accompanies lupus looked like the bite of a wolf. There are four categories of lupus: systemic lupus erythematosus, cutaneous lupus, drug-induced systemic lupus erythematosus, and neonatal lupus (see “Pregnancy” in Chapter Four). *Lupus: A Patient Care Guide for Nurses and Other Health Professionals* is concerned primarily with systemic lupus erythematosus.

Systemic lupus erythematosus (SLE, or lupus) is a chronic, inflammatory, multisystem disorder of the immune system. In SLE, the body develops antibodies that react against the person’s own normal tissue. These antibodies are markers for SLE, and are one indicator of many immune system abnormalities that lead to clinical manifestations.

The course is unpredictable and individualized; no two patients are alike. Lupus is not contagious, infectious, or malignant. It usually develops in young women of childbearing years, but many men and children also develop lupus. SLE also appears in the first-degree relatives of people with lupus more often than it does in the general population, which indicates a hereditary component. However, most cases of SLE

occur sporadically, indicating that both genetic and environmental factors play a role in the development of the disease.

Lupus varies greatly in severity, from mild cases requiring minimal intervention to those in which significant and potentially fatal damage occurs to vital organs such as the lungs, heart, kidneys, and brain. For some patients, the disease can be characterized by “flares” of activity interspersed with periods of improvement or remission. A flare, or exacerbation, is increased activity of the disease process with an increase in physical manifestations and/or abnormal laboratory test values. Periods of improvement may last weeks, months, or even years. Other patients have continuous, or chronic, activity.

Although remissions are unusual, some patients never develop severe manifestations, and the outlook is improving for patients who do develop them.

Cutaneous lupus, which affects primarily the skin, is common among patients with lupus erythematosus. The most prevalent and severe form of cutaneous lupus is called chronic cutaneous lupus. It is commonly known as discoid lupus, but it has other forms as well (see “Dermatologic Manifestations” in Chapter 4).

Drugs Implicated as Activators of Drug-Induced Lupus

Drugs with proven association

- Isoniazid
- Hydralazine
- Procainamide
- Minocycline
- Anti-TNF biologics

Drug-induced lupus erythematosus develops after the use of certain drugs or biologics and has symptoms similar to those of SLE. The characteristics of this syndrome are pleuropericardial inflammation, pleuritic chest pain, pericarditis, fever, rash, and arthritis. Serologic changes can occur. The clinical and serologic signs usually subside gradually after the offending drug is discontinued. A wide variety of drugs is implicated in this form of lupus (see box, above). More recently, the newer TNF (tumor necrosis factor) inhibitors used to treat rheumatoid arthritis, Crohn's disease, and ankylosing spondylitis have been associated with the development of lupus symptoms. As with lupus triggered by other drugs, the symptoms resolve when the agent is stopped.

Symptoms of SLE

Early symptoms of SLE might be vague, nonspecific, and easily confused with other pathological and functional disorders. Symptoms may be transient or prolonged, and individual symptoms often appear independently of the others. Moreover, a patient may have severe symptoms with few abnormal laboratory test results, and vice versa. The box on the next page lists the range of clinical symptoms seen in patients with lupus over the lifetime of the disease.

Diagnosis of SLE

The onset of lupus may be acute, resembling an infectious process, or it may be a progression of vague symptoms over several years. As a result, diagnosing SLE is often a challenge. A consistent, thorough medical examination by a doctor familiar with lupus is essential to an accurate diagnosis. This must include a complete medical history and physical examination, laboratory tests, and a period of observation (possibly years). The doctor, nurse, or other health professional assessing a patient for lupus must keep an open mind about the varied and seemingly unrelated symptoms that the patient may describe. For example, a careful medical history may show that sun exposure, use of certain drugs, viral disease, stress, or pregnancy aggravates symptoms, providing a vital diagnostic clue.

Symptoms of SLE

- Fatigue
- Arthralgia
- Arthritis
- Fever (>100 °F)
- Skin rashes
- Anemia
- Edema
- Pleurisy
- Facial rash
- Photosensitivity
- Alopecia (hair loss)
- Raynaud's phenomenon
- Seizures
- Mouth or nose ulcers

No single laboratory test can definitely prove or disprove SLE. Initial screening includes a complete blood count (CBC); liver and kidney screening panels; laboratory tests for specific autoantibodies (e.g., antinuclear antibodies [ANA]) such as anti-Ro, anti-La, anti-dsDNA, anti-Sm, anti-RNP, lupus anticoagulant, and anticardiolipin; an anti-phospholipid antibody test; urinalysis; blood chemistries; and erythrocyte sedimentation rate (ESR). Abnormalities in these test results will guide further evaluations. Anti-dsDNA antibody or anti-Sm antibody are autoantibodies found only in lupus. Specific immunologic studies, such as those of complement components (e.g., C3 and C4) and other autoantibodies (e.g., anti-La, anti-Ro, anti-RNP), can be helpful in diagnosis. At times, biopsies of the skin or kidney using immunofluorescent staining techniques can support a diagnosis of SLE (see

Chapter 3, *Laboratory Tests Used to Diagnose and Evaluate SLE*, for further information). A variety of laboratory tests, x rays, and other diagnostic tools are used to rule out other pathologic conditions and to determine the involvement of specific organs. It is important to note, however, that any single test may not be sensitive enough to reflect the intensity of the patient's symptoms or the extent of the disease's manifestations.

The American College of Rheumatology (ACR), an organization of doctors and associated health professionals who specialize in arthritis and related diseases of the bones, joints, and muscles, has developed and refined a set of classification criteria (see box, next page). If at least 4 of the 11 criteria develop at one time or individually over any period of observation, then the patient can be classified as an SLE patient for research purposes. However, a diagnosis of SLE can be made in a patient having fewer than four of these symptoms.



Treatment of SLE

The treatment of SLE is as varied as its course. Although there is no cure for lupus and it is difficult to predict which treatment will be most effective for each patient, there have been significant gains in treating patients, and there is general consensus on several treatments.

A conservative regimen of physical and emotional rest, protection from

direct sunlight, a healthful diet, prompt treatment of infections, and avoidance of aggravating factors are the mainstays of lupus therapy. In addition, for female patients, pregnancy must be planned for times when the disease is under control, and the patient is on allowable medications.

American College of Rheumatology Criteria for Classifying SLE for Research Purposes

- Malar rash
- Discoid rash
- Photosensitivity
- Oral ulcers
- Arthritis
- Serositis (pleuritis or pericarditis)
- Renal disorder (persistent proteinuria or cellular casts)
- Neurological disorder (seizures or psychosis)
- Hematologic disorder (anemia, leukopenia or lymphopenia on two or more occasions, thrombocytopenia)
- Immunologic disorder (abnormal anti-dsDNA or anti-Sm, positive antiphospholipid antibodies)
- Abnormal ANA titer

Source: Tan E. The 1982 criteria for the classification of systemic lupus erythematosus (with revisions in 1997). *Arthritis and Rheumatism* 1982;25:1271-1277. © 1982 American College of Rheumatology. Used with permission of Lippincott-Raven Publishers.

Physical Rest

This basic component of everyone's good health is essential for the person with lupus. The fatigue of lupus is not sleepiness or tiredness from physical exertion, but rather a frequent, persistent complaint often described as a "bone-tired feeling" or a "paralyzing fatigue." Normal rest often does not refresh the patient or eliminate the tiredness due to lupus, and fatigue may persist despite normal laboratory test results. The patient and family need instruction on how to use this tiredness as a guide for scheduling activity and rest. It must be reinforced that this need for rest is not laziness. Eight to 10 hours a night of restful sleep, naps, and "timeouts" during the day are basic guidelines. Physical activity should be encouraged as the patient can tolerate it.

However, in some patients, the fatigue is more related to fibromyalgia than to the activity of their lupus. An individualized exercise routine may promote well-being, especially in a patient with fibromyalgia. Some scientists believe that the incidence of fibromyalgia is increased in patients with lupus. They do not know why, but one hypothesis is that inflammation from lupus may lead to the rewiring of the pain pathways in the central nervous system.

Emotional Rest

A patient's emotional stressors should be carefully assessed, because they may play a role in triggering a flare. The patient should be instructed on how to avoid these stressful situations. However, the physical manifestations of lupus must be treated as they present themselves while the emotional stresses are explored. Discussions with family members on this issue are essential for providing them with information and obtaining their support. Counseling for both the patient and the family may be an option. Chapter 6, *Psychosocial Aspects of Lupus*, explores these issues in further detail.

Protection from Direct Sunlight

An abnormal reaction to the ultraviolet (UV) rays of the sun, photosensitivity results in the development or exacerbation of a rash that is sometimes accompanied by systemic symptoms. Photosensitivity is common in Caucasian patients. All people with lupus should avoid direct, prolonged exposure to the sun. Sun-sensitive patients should frequently apply a sunscreen. The best sunscreen is one that protects against both UVA and UVB rays. To get adequate protection, patients should be advised to select either a "broad-spectrum protection" sunscreen with an SPF of at least 15, or one that contains micronized zinc oxide or titanium dioxide, both of which block UVA and UVB light. Sun-sensitive patients should also avoid unprotected exposure between 10 a.m. and 4

p.m., and wear protective clothing, such as wide-brimmed hats and long sleeves. In severe cases, patients may wish to purchase special UV-blocking clothing. People with lupus should be aware that UV rays are reflected off water and snow, and that glass, such as car windows, does not provide total protection from UV rays.

People with lupus should also know that fluorescent and halogen lights may emit UV rays and can aggravate lupus. This may be an issue for patients who work indoors, in places with these kinds of lights. Sunscreen and protective clothing can help minimize exposure, and plastic devices are available that block UV emissions from fluorescent or halogen light bulbs.

Diet and Nutrition

A well-balanced diet is essential in maintaining good health for all people, including people with lupus. A low-fat, low-cholesterol diet is recommended, given the increased risk of heart disease in SLE. When fluid retention, hypertension, kidney disease, or other problems are present, a restricted diet plan may be prescribed. Also, food intolerances and allergies may occur. The health professional should make a note of the patient's dietary history and suggest diet counseling if appropriate, especially if the patient has a problem with weight gain, weight loss, gastrointestinal (GI) distress, or food intolerances. Nutritional considerations in treating people with lupus are discussed further in Chapter 4, *Care of the Lupus Patient*.

Treatment of Infection

Prompt recognition and treatment of infection is essential for those with lupus. However, cardinal signs of infection may be masked because of SLE treatments. For example, a fever may be suppressed because anti-inflammatory therapy is being given. When an infection is being treated, the health professional should be alert to medication reactions, especially to antibiotics. Sulfonamide antibiotics may increase the risk of a lupus flare.

Pregnancy and Contraception

Spontaneous abortion and premature delivery are more common for women with SLE than for healthy women. To minimize risks to both mother and baby, a pregnant woman with lupus should be closely supervised by an obstetrician familiar with lupus and high-risk pregnancies. As long as a woman is not hypercoagulable, oral contraceptives may be considered for contraception, as they do not increase flares.

Surgery

Surgery may exacerbate the symptoms of SLE. Hospitalization may be required for otherwise minor procedures, and postoperative discharge may be delayed. If it is elective, the surgery should be postponed until lupus activity is under control.

Immunizations

Immunizations with killed vaccines have not been shown to exacerbate SLE. Influenza and pneumococcal vaccines are routinely recommended for SLE patients. A patient with lupus should consult her or his doctor before receiving any immunizations, even routine ones.



Medications for SLE

Some patients never require medications, and others take them only as needed or for short intervals, but many require constant therapy with variable doses. Despite their usefulness, no drugs are without risks. Medications frequently used to control the symptoms are nonsteroidal anti-inflammatory drugs (NSAIDs), antimalarials, corticosteroids, immunosuppressives, and intravenous immunoglobulins. Other medications may be necessary to control specific manifestations. Before prescribing a medication, it is helpful to scrutinize a patient's past response to treatments. A careful drug history should be taken; in particular, hypersensitivities or allergies to certain drugs should be noted. Patient and family education about medications and their side effects is essential. Chapter 5, *Medications Used to Treat Lupus*, presents more detailed information on this issue, and Chapter 7, *Patient Information*, includes relevant information for patients.



Psychological Aspects

For the patient with lupus, the emotional aspects of dealing with a chronic disease can be overwhelming. They can also make the patient feel isolated from friends, family, and coworkers. Grief, depression, and anger are common reactions of patients with lupus.

Those with lupus and their families deal with the disease in strikingly different ways. Managing the ups and downs of the disease may put strains on relationships and marriages. Younger patients may fail to assert their independence or develop a life away from home if they feel they cannot cope with their disease on their own. Family members are often confused and frightened over the changes they see. They need guidance on and constructive suggestions for helping the patient. Children of people with lupus, particularly those too young to really understand the disease, may need special help in coping with their parent's illness. It is in these areas that the patient, family, and support systems need to be assessed, encouraged, and guided so that they work together as a team. By allowing the patient and her or his family the time and freedom to move through different emotional phases without criticism and unrealistic expectations, you will facilitate acceptance of the disease. The health professional can have a major role in helping a patient adjust, and can help with referrals to a social worker, counselor, or community resource, if needed. Chapter 6, *Psychosocial Aspects of Lupus*, discusses these issues in more detail.



Health Care Implications

The psychosocial issues involved in defining, diagnosing, and treating lupus have implications for the way the nurse or other health professional works with a patient who has lupus. For example, a person who is newly diagnosed with lupus needs help in getting current, accurate information about the disease and in defining realistic expectations and goals. The Patient Information Sheets in Chapter 7 can help. The health professional can clarify information with the patient's doctor, make rounds with the doctor, and act as a liaison between the patient and the doctor, if needed. Frequently, many doctors are involved in caring for a patient with lupus at one time. This may increase the patient's confusion and leave gaps in information. Emotional support for the patient is essential. Being available for questions, providing reassurance, and encouraging discussion of fears and anxieties are all crucial roles that the nurse can play.

The person with lupus who is hospitalized during a flare requires symptomatic nursing care. It is important to note that objective data, such as anemia or sedimentation rate, may not support subjective complaints of fatigue or pain. Careful head-to-toe assessment and documentation of all symptoms and complaints are important. Symptomatology changes constantly, so frequent reassessment is necessary. Reevaluations validate a patient's concerns and alert the doctor to changes that may be transient yet significant.

The patient's tolerance for physical activity and need to control what she or he can do should be respected. The patient should be involved in developing a care plan and daily schedule of activities.

The best way to treat lupus is to *listen to the patient*, whether she or he was diagnosed today or years ago. The patient's support systems can be expanded to include pamphlets and books, physical or occupational therapy, vocational rehabilitation, homemaker services, the Visiting Nurses Association (VNA), the Lupus Foundation of America (LFA), the SLE Foundation, and the Arthritis Foundation (AF).

Lupus is a challenge to everyone concerned. The health professional has a key role in its management. Accurate documentation, supportive care, emotional support, patient education, and access to community resources will provide the patient and her or his family with the tools they need to cope effectively.

Chapter 2

Advances in Lupus Research



Scientists know that systemic lupus erythematosus (SLE) is an autoimmune disease, and recent studies have begun to unravel some of the elements involved. Genetic, environmental, and hormonal factors are all believed to play roles in causing lupus. Much research is being conducted to understand these factors and how they work together.

Epidemiological studies may yield further clues about the cause of lupus. For example, SLE is more prevalent in women, especially those in the reproductive years, than in men. And while people of all ethnicities get lupus, the incidence rate for Asian women (particularly those of Chinese and Filipino descent) and African American women is three to four times higher than it is for Caucasian women. African American women also tend to develop the disease at a younger age, develop more serious complications, and have a higher mortality rate from the disease than do Caucasian women. Researchers are trying to find out why lupus is more common in these populations.

Health professionals continue to search for better ways to care for people with lupus. Understanding what causes the disease and why certain people are more likely to develop it may one day lead to promising new treatments for, or even prevention of, lupus. In the meantime, researchers continue to look for new treatments and ways to modify existing ones so they can diminish or eliminate side effects and improve the quality of life for people who have lupus.

During the last 15 years, researchers have made a tremendous amount of progress in lupus research. The number of studies on this disease has increased exponentially, and most researchers believe that answers to some of the key questions are close at hand. This chapter highlights some of the recent research advances in lupus and provides an overview of the direction of current research.



Etiology

Investigators have found evidence to support several likely possibilities in the etiology of SLE. Some believe there may be more than one type of SLE and that its etiology may vary from one person to the next. Current studies are focusing on the following elements:

- immune system dysfunction
- genetics
- environmental influences
- hormones

In lupus research, as in many areas of research, animal models have played an important role. This discussion of the

etiology of lupus includes examples of research conducted in animal models that illustrate how these factors might influence the development of SLE in humans.

Immune System Dysfunction

Lupus is known as an autoimmune disease because a person's immune system attacks the body's own tissues. In lupus, the signs and symptoms of the disease can be attributed to damage caused directly by autoantibodies, the deposition of immune complexes (the combination of antigen and autoantibody), or cell-mediated immune mechanisms. Various steps are involved in these mechanisms, and scientists hope to reveal the cause of lupus by examining each step. In the process of doing so, they also may find new ways to treat lupus.

One of the hallmarks of lupus is the formation of autoantibodies, which are antibodies that react with a person's own tissue. Autoantibodies occasionally can be present in healthy people, but they are typically found in low concentrations. Essentially all patients with lupus have autoantibodies, generally in high concentrations. The most characteristic autoantibodies are antinuclear antibodies. They are so called because they generally target the nucleic acids, proteins, and ribonucleoprotein complexes inside a cell's nucleus. Other autoantibodies in people with lupus also can bind to cell surface membranes and destroy cells directly or bind to circulating proteins.

Research studies have shown an association between the presence of certain autoantibodies and particular manifestations of lupus, such as kidney or skin disease. Scientists are now trying to establish whether these autoantibodies actually cause signs or symptoms of lupus. However, most people with lupus test positive for many different autoantibodies, so it is often very difficult to identify which autoantibodies are responsible for a specific type of tissue damage in human subjects.

In lupus, the immune system produces too many autoantibodies and forms too many immune complexes. Normally, antigen-antibody immune complexes are joined by complement, a substance in the blood that aids in the breakup and removal of immune complexes from the body. Scientists have found that SLE patients have both inherited and acquired abnormalities in complement and complement receptors. These deficiencies in complement may decrease the body's ability to get rid of immune complexes. Immune complexes that are not broken up may be deposited in various body tissues, leading to the inflammation that results in tissue damage. Scientists continue to study:

- the nature of immune complexes and what happens to them once they are formed
- the nature of the autoantibodies that make up the immune complexes
- the reason for increased production of autoantibodies.

Genetics

There is considerable evidence showing that genes play a role in the etiology of lupus. The extremely high occurrence of lupus in both members of a pair of identical twins and the increased prevalence of lupus among first- and second-degree relatives of people with lupus suggests a genetic component. In addition, when researchers look at autoantibodies typically found in a lupus patient and her or his siblings and compare them with clinical manifestations of the disease in the individuals, they find that the individuals have the autoantibodies in common more often than they have the clinical manifestations in common. This finding indicates a genetic basis for the formation of autoantibodies that play a role in lupus.

Studies to date suggest that many different genes contribute to lupus susceptibility and that no single genetic abnormality causes the disease. It also appears that genes may be influential in determining the type or severity of lupus. Genes that have been associated with lupus in humans include:

- the immune system genes human leukocyte antigen (HLA)-DR3 (and B8 in older data), HLA-DR2, and complement C4 genes; other HLA-DR alleles; and alleles at HLA-DQ
- genes that control immune complex deposition and programmed cell death.

Researchers studying lupus in animals have discovered a single gene that causes a lupus-like illness in mice.

In these mice, the *fas* gene, one of the genes that controls apoptosis (programmed cell death), is defective. When the defective *fas* gene is replaced with a normal gene, the mice no longer develop signs of the disease.

Scientists continue to study the genetics of lupus in humans and in animals. If the genes that create a predisposition for lupus can be identified, it may be feasible to correct genetic defects through gene therapy or other treatments. At this time, researchers are studying:

- genes associated with the clearance of immune complexes
- genes associated with immune abnormalities in lupus
- genes associated with apoptosis.

Glossary of Immunologic and Genetic Terms

Allele – one of the two or more forms of a gene

Complement receptors
– molecules on the surface of cells that react with complement

Intranuclear nucleic acids
– deoxyribonucleic acid (DNA) and ribonucleic acid (RNA) found inside the nucleus of the cell

Polymorphism – a genetic characteristic that can be physically manifested in more than one form

Ribonucleoprotein complexes
– molecules containing ribonucleic acids (RNA) and protein

Environmental Influences

Researchers believe that genetic predisposition is just one piece of the puzzle of lupus etiology. Studies have shown that the occurrence of lupus is high among both members of a pair of identical twins and much lower among nonidentical twins and other full siblings. The fact that this concordance is not 100 percent among identical twins, however, suggests that environmental agents probably trigger lupus in individuals with a genetic predisposition. Environmental factors that scientists are considering include sunlight, stress, certain chemical substances, toxic exposures, and infectious agents such as viruses.

Sunlight

Exposure to the ultraviolet (UV) rays of sunlight can lead to a skin rash and exacerbate systemic manifestations of lupus. Exposure to UVA or UVB light causes certain cellular proteins to accumulate in abnormally large amounts on the cell's surface. These proteins react with autoantibodies commonly found in people with SLE, leading to a local or systemic inflammatory response.

Stress

Doctors suspect stress is a possible trigger for lupus flares. Frequently, patients ascribe their first symptoms or worsening symptoms to a stressful event, such as divorce, death of a loved one, or job loss. Scientists do not have a clear explanation for this phenomenon, but research is being done to find out whether stress hormones such as

adrenaline or cortisone may influence the development or course of the disease.

Chemical Substances

A number of drugs cause a lupus-like illness in susceptible individuals. These include chlorpromazine, hydralazine, isoniazid, methyldopa, and procainamide, as well as TNF (tumor necrosis factor) inhibitors such as etanercept (Enbrel®) and infliximab (Remicade®), which are used for rheumatoid arthritis. When the offending drug is stopped, the lupus symptoms resolve. When researchers determine how these drugs cause lupus, they may be able to provide further answers on the etiology of SLE. Some drugs can precipitate flares of SLE, including sulfonamides, sulfonamide antibiotics, and echinacea.

Toxic Exposures

Several toxic exposures have been associated with SLE. These include silica and mercury.

Environmental crystalline silica exposure has been associated with the formation of autoantibodies and the development of SLE and other autoimmune disease.

A National Institutes of Health (NIH)-funded epidemiological study published in 2002 by the American College of Rheumatology found that silica exposure “may promote the development of SLE in some individuals.” In a 2005 study funded partly by the NIH, researchers found that autoimmune-prone New Zealand mice that were exposed to silica experienced increases in autoantibodies and glomerulonephritis.

Animal studies have established a connection between exposure to mercury and lupus-like autoimmune disease. Additionally, case studies in humans have demonstrated a correlation between accidental mercury exposure and the onset or increased severity of autoimmune disease symptoms. Two ongoing studies funded by the National Institute of Environmental Health Sciences are examining the biochemical, molecular, and genetic mechanisms underlying mercury-induced autoimmunity.

Viruses

Many researchers suspect that infectious agents such as viruses may trigger lupus by somehow disrupting cellular immune function in susceptible individuals. It is possible that a virus can infect B cells (cells programmed to produce antibodies in response to specific antigens) and cause them to produce autoantibodies. Research provides evidence that antibodies produced to fight viruses such as the Epstein-Barr virus crossreact with bodily proteins in genetically susceptible people. Researchers are continuing to study various mechanisms by which viruses could result in autoimmunity.

Hormones

SLE is more prevalent in women during their reproductive years. In addition, disease activity sometimes flares during pregnancy or during the postpartum period. For these reasons, researchers have long considered that hormones may influence lupus. Some research in animals also supports this supposition. Lupus-like illnesses in animals are exacerbated when they receive female hormones.

A recent study showed that oral contraceptives do not increase flares in SLE, but hormone therapy does cause an increase in mild-to-moderate (though not severe) flares.



Treatment and Health Maintenance

Improving current treatments for people with lupus and improving the reproductive health of women with lupus are also important elements of ongoing lupus research. Specifically, investigators are studying ways to:

- optimize the use of immunosuppressives, such as corticosteroids and cyclophosphamide, and decrease unwanted side effects
- develop new therapies with fewer side effects
- correct underlying immune abnormalities
- improve reproductive health in women with lupus.

Optimize the Use of Immunosuppressives

Corticosteroids, such as prednisone, are a mainstay of lupus therapy because they suppress the immune system and reduce inflammation. Unfortunately, they also cause some serious side effects, including weight gain, hypertension, diabetes, cataracts, glaucoma, infections, osteonecrosis, osteoporosis, and coronary artery disease. Other, less serious, side effects can also take a toll on the

patient's quality of life. Scientists are investigating how corticosteroid use can be minimized in such a way that the benefits are retained while the side effects are reduced.

Cyclophosphamide also suppresses the immune system and has anti-inflammatory properties. Treatment with cyclophosphamide improves many severe manifestations of lupus. Unfortunately, cyclophosphamide can produce serious toxicities. Patients using this drug may experience nausea and vomiting, alopecia, and an increased risk for infections. In the long term, cyclophosphamide also may damage gonadal tissue and lead to ovarian or testicular failure. Other potential long-term complications include hemorrhagic cystitis, bladder fibrosis, bladder cancer, and other cancers such as lymphoma. At this time, scientists are conducting studies to better understand the long-term effects of cyclophosphamide therapy. In addition, they are exploring the use of additional drugs that might counteract some of the negative side effects of cyclophosphamide. For example, they have found that giving leuprolide (Lupron®) to a woman 2 weeks before each cyclophosphamide infusion can reduce the risk of premature ovarian failure resulting in infertility. They are also trying to determine the dose regimen of cyclophosphamide that is most effective and causes the fewest severe side effects.

Mycophenolate mofetil (CellCept®) is another immunosuppressant used to treat severe lupus; however, it is not approved by the Food and Drug

Administration (FDA) for people with lupus. (It is FDA-approved for preventing rejection of kidneys by patients receiving transplants.) Several clinical trials have proven the benefit of mycophenolate mofetil for lupus nephritis.

Mycophenolate acts through the inhibition of T and B cell function. Possible side effects include diarrhea, low white blood cell counts, and certain viral infections. There is also concern that long-term use will increase the risk of malignant cancers later in life.

Scientists are also trying to identify combination therapies that may be more effective than single-treatment approaches. For example, in lupus nephritis patients with moderate kidney scarring, a combination of cyclophosphamide and prednisone is more effective in preserving renal function than is treatment with prednisone alone. In these patients, the combination therapy reduces the likelihood of end-stage renal failure.

Develop New Therapies

While some researchers are examining existing drug and treatment practices, other researchers are developing new treatment regimens. Promising areas of treatment research include biologic agents and hormones.

Biologic Agents

On the basis of new information about the SLE disease process, scientists are using novel biologic agents to selectively block parts of the immune system.

Developing and testing these new drugs, which are based on compounds that occur naturally in the body, is an exciting and promising new area of lupus research. One such agent is rituximab, a monoclonal antibody that lowers B cell counts and is approved for lymphoma treatment. In several series of patients with clinically active lupus, a single injection of the agent brought significant improvement in symptoms. Epratuzumab, another monoclonal antibody that may work by modulating B cell function, is in phase III clinical trials for moderate-to-severe lupus.

Another biologic agent is LymphoStat-B® (belimumab), a human monoclonal antibody that recognizes and inhibits the biological activity of B-lymphocyte stimulator or BLYS. Laboratory and observational studies have indicated that higher than normal levels of BLYS may play a role in autoimmune diseases, such as SLE and rheumatoid arthritis. LymphoStat-B® is being studied as potential treatment for these diseases.

Hormones

Because hormones are believed to influence the course and perhaps even the etiology of lupus, many researchers are interested in testing the effects of hormones on people with lupus. For example, animal and human studies have shown benefits associated with dehydroepiandrosterone (DHEA) therapy. DHEA is a naturally occurring hormone present in unusually low concentrations in women with lupus. In clinical trials, DHEA reduced the prednisone requirements for patients and reduced flares.¹

¹ DHEA is not approved by the U.S. Food and Drug Administration for treatment of lupus.

Other research is showing that other hormone preparations that were once thought to worsen lupus – such as hormone replacement therapy and oral contraceptives – may be safe for some women with the disease.

Correct Underlying Immune Abnormalities

Researchers predict that one day it may be possible to correct the underlying immune abnormalities in people with lupus. Studies are underway to explore the dimensions, risks, and benefits of reconstructing the immune system by high-dose cyclophosphamide with or without stem cell rescue.

Improve Reproductive Health in Women with Lupus

Because of recent improvements in diagnostic tools for lupus and a better understanding of the disease, doctors can now predict the likelihood of a lupus-related miscarriage and identify women at risk for giving birth to babies with neonatal lupus. Doctors and people with lupus can now take measures to prevent miscarriages, and doctors can prepare to treat those babies born with neonatal heart block, the most serious complication of neonatal lupus.

Progress is also being made in another important area of reproductive health. In the past, women with lupus have not been able to use oral contraceptives or

take advantage of hormone replacement therapy because of concerns that estrogens exacerbate lupus. However, recent results of a major study, Safety of Estrogen in Lupus Erythematosus National Assessment (SELENA), funded by the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), the NIH Office of Research on Women's Health, and the National Center on Minority Health and Health Disparities, suggest that oral contraceptives do not increase flares in women with SLE. Women with antiphospholipid antibodies cannot take oral contraceptives, however, because of the increased risk of blood clots.



Role of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)

NIAMS leads and coordinates the Federal biomedical research effort in lupus by conducting and supporting research projects, research training, clinical trials, and epidemiologic studies and by disseminating information on research results.

NIAMS funds many scientists across the United States who are studying the causes and mechanisms of tissue injury in SLE and the reasons why lupus strikes women and certain minority populations more frequently.

In addition, NIAMS has established the first Specialized Centers of Research (SCORs) devoted to lupus. These centers enable basic scientists and clinicians to collaborate closely on lupus research.

To further the study of the genetics of lupus and to provide a resource for all researchers in this field, NIAMS has established a lupus registry and repository. Researchers who study families in which two or more members have been diagnosed with lupus collect and continually update clinical, demographic, and laboratory data on these individuals and submit the data to the lupus registry. Blood, cell, and tissue samples and DNA from these individuals will be stored in the lupus repository.

The registry and repository will allow all lupus researchers access to an enormously valuable database of information on people with lupus. For example, researchers will be able to analyze each DNA sample in the repository for the presence of a standard set of genetic markers. A centralized database will maintain this genetic information along with clinical and laboratory information from the registry. Together, these data can be used as the starting point for genetic analysis to identify possible lupus genes. Finding the genes that cause the disease may help researchers develop new treatments. In addition, this research will help identify which people with lupus will develop the most severe manifestations of the disease. This will help doctors decide who needs the most aggressive treatment.

In February 2003, Congress called on the Office of the Secretary of the Department of Health and Human Services (DHHS) to establish a Federal working group on lupus to exchange information and coordinate Federal efforts regarding lupus research and education initiatives. As the lead institute at the NIH for lupus research, NIAMS was asked to direct this Federal working group. The group is composed of representatives from all relevant DHHS agencies and other Federal departments having an interest in lupus.

Research advances of the past have led to significant improvements in the prognosis for patients with lupus. As current research efforts unfold, there is continued hope for new treatments, further improvements in patient quality of life, and ultimately, for ways in which to prevent or cure the disease.

Chapter 3

Laboratory Tests Used to
Diagnose and Evaluate Lupus



Lupus is characterized by abnormalities in many laboratory test results. These abnormalities are different for every patient and they vary significantly during the course of a patient's disease. The serial evaluation of an individual's tests along with the physician's observations and the patient's history determine the diagnosis of systemic lupus erythematosus (SLE), its course, and the treatment regimen. All laboratory values must be interpreted in light of the patient's present status, other correlating laboratory test results, and coexisting illnesses. This chapter briefly describes the major tests used to diagnose and evaluate SLE and provides information on their rationale and clinical usefulness. Nurses and other health professionals should consult rheumatologists, manuals of laboratory and diagnostic tests, or hospital clinical laboratory departments for further information on possible interpretations of results from these tests and their implications for SLE.



Tests for Blood Cell Abnormalities

Blood cell abnormalities often accompany SLE. People suspected of having lupus are usually tested for anemia, leukopenia, and thrombocytopenia.

Anemia

Tests for anemia include those for hemoglobin, hematocrit, and red blood cell (RBC) counts. In addition, the levels of iron, total iron-binding capacity, and ferritin may be tested. At any time during the course of the disease, about 40 percent of patients with SLE will be anemic. The anemia may be caused by iron deficiency, gastrointestinal (GI) bleeding, medications, and autoantibody formation to RBCs, or “chronic disease.” When first diagnosed, about 50 percent of patients have a form of anemia in which the concentration of hemoglobin and the size of the RBCs are normal. This is called normochromic-normocytic anemia, or “anemia of chronic disease.” Autoimmune hemolytic anemia, with a positive Coombs test, is much less common.

Leukopenia and Thrombocytopenia

Abnormalities in the white blood cell (WBC) and platelet counts are an important indicator of SLE. Leukopenia, a decrease in the number of WBCs, is very common in active SLE and is found in 15 to 20 percent of patients.

Leukopenia can occur from lupus or from prednisone. Thrombocytopenia, or a low platelet count, occurs in 25 to 35 percent of patients with SLE. This can be serious problem when platelet count is very low.



Measurements of Autoimmunity

When certain autoantibodies are present, this provides valuable diagnostic information for SLE. The most specific tests are those that detect high levels of these autoantibodies. The most common and specific tests for autoantibodies and other elements of the immune system are listed first.

Antinuclear Antibody (ANA)

A screening test for ANA is standard in assessing SLE because it is positive in close to 100 percent of patients with active SLE. However, it is also positive in 95 percent of patients with mixed connective tissue disease, in more than 90 percent of patients with systemic sclerosis, in 70 percent of patients with primary Sjögren’s syndrome, in 40 to 50 percent of patients with rheumatoid arthritis, and in 5 to 10 percent of patients with no systemic rheumatic disease. Patients with SLE tend to have high titers of ANA. False-positive results are found during the course of chronic infectious diseases, such as subacute bacterial endocarditis, tuberculosis, hepatitis, and malaria. The sensitivity and specificity of ANA determinations depend on the technique used.

Anti-Sm

Anti-Sm is an immunoglobulin specific against Sm, a ribonucleoprotein found in the cell nucleus. This test is highly specific for SLE; it is rarely found in patients with other rheumatic diseases. However, only 30 percent of patients with SLE have a positive anti-Sm test.

Anti-dsDNA

Anti-dsDNA is an immunoglobulin specific against native (double-stranded) DNA. This test is highly specific for SLE; it is not found in patients with other rheumatic diseases. Fifty percent of patients with active SLE have a positive anti-dsDNA test. For many patients with anti-dsDNA, the titer is a useful measure of disease activity. The presence of anti-dsDNA is associated with a greater risk of lupus nephritis.

Anti-Ro(SSA) and Anti-La(SSB)

These immunoglobulins, commonly found together, are specific against RNA proteins. Anti-Ro is found in 30 percent of SLE patients and 70 percent of patients with primary Sjögren's syndrome. Anti-La is found in 15 percent of people with lupus and 60 percent of patients with primary Sjögren's syndrome. Anti-Ro is highly associated with photosensitivity; both are associated with neonatal lupus.

Complement

Complement proteins constitute a serum enzyme system that helps mediate inflammation. Complement components

are triggered into an activated form by such immunologic events as interaction with immune complexes. Complement components are identified by numbers (C1, C2, etc.). Genetic deficiencies of C1q, C2, and C4, although rare, are commonly associated with SLE. A test to evaluate the entire complement system is called CH50. The most commonly measured complement components are the serum levels of C3 and C4.

Erythrocyte Sedimentation Rate (ESR) and C-Reactive Protein (CRP)

Tests for ESR and CRP are nonspecific tests to detect generalized inflammation. Levels are generally increased in patients with active lupus and decline when corticosteroids or nonsteroidal anti-inflammatory drugs are used to reduce inflammation. However, they do not directly reflect disease activity.

Antiphospholipid Antibodies (APLs)

APLs are autoantibodies that react with phospholipids. Recent data indicate that APLs recognize a number of phospholipid-binding plasma proteins (e.g., prothrombin, β_2 glycoprotein I) or protein-phospholipid complexes rather than phospholipids alone. APLs are present in 50 percent of people with lupus. Antiphospholipid syndrome occurs in 50 percent of SLE patients who have the lupus anticoagulant. This syndrome is characterized by a persistently positive lupus anticoagulant or medium-to-high titer anticardiolipin or anti- β_2 glycoprotein I in the clinical setting of thrombosis, fetal loss, multiple

first-trimester losses, or preterm birth from severe placental vasculopathy.

APLs and antiphospholipid syndrome may also occur in patients without lupus (primary antiphospholipid syndrome). APLs are detected in three types of laboratory assays:

- **lupus anticoagulants.** Lupus anticoagulants are APLs that inhibit certain coagulation tests, such as the activated partial thromboplastin time (aPTT), dilute Russell viper venom time (dRVVT), and kaolin clotting time (KCT). Although the antibodies act as anticoagulants in these laboratory assays, they are not clinically associated with hemorrhage, but with thrombosis, pregnancy loss, and other manifestations of the antiphospholipid syndrome. Most lupus anticoagulant antibodies are directed against $\beta 2$ glycoprotein I or prothrombin.
- **anticardiolipin antibodies (ACA).** Sensitive enzyme-linked immunoabsorbent assays (ELISAs) using cardiolipin as the putative antigen are commonly performed to detect APLs. In patients with antiphospholipid syndrome, most antibodies detected in anticardiolipin ELISAs are directed against cardiolipin-bound $\beta 2$ glycoprotein I.
- **anti- $\beta 2$ glycoprotein I.** Because ELISAs do not recognize cardiolipin unless $\beta 2$ glycoprotein I is present, anti- $\beta 2$ glycoprotein detection assays

have been developed. These assays have revealed that anti- $\beta 2$ glycoprotein I antibodies may be more strongly associated with antiphospholipid syndrome than are anticardiolipin antibodies.



Tests for Kidney Disease

Several tests can be done to assess a patient for kidney disease.

Measurement of Glomerular Filtration Rate and Proteinuria

The glomerular filtration rate is a measure of the efficiency of kidneys in filtering blood to excrete metabolic products. Typically this is done by collecting a 24-hour urine sample for measurement of creatinine clearance. Impairment of renal function by lupus nephritis results in reduced levels of creatinine clearance. The 24-hour urine sample can also quantify protein loss.

Protein/Creatinine Ratio

Performed on a one-time voided specimen, rather than from a 24-hour collection, this test is useful as a measure of protein loss and is more convenient for patients.

Urinalysis

Urinalysis can indicate the presence or extent of renal disease. For example, proteinuria can be a reliable indicator of renal disease. The presence of RBCs,

WBCs, and cellular casts, particularly red cell casts, in the urine also indicates renal disease.

Measurement of Serum Creatinine Concentration

Creatinine is a waste product of muscle metabolism that is excreted by the kidneys. Loss of renal function as a consequence of lupus nephritis causes increases in serum levels of creatinine. The concentration of creatinine in the serum can be used to assess the degree of renal impairment.

Kidney Biopsy

Kidney biopsy can be used to determine the presence of immune complexes and the presence, extent, and type of inflammation in the glomeruli. Diagnosing the extent and type of inflammation may help to determine a treatment program for lupus.

Chapter 4

Care of the Lupus Patient



Lupus symptoms tend to present themselves according to the body system affected. These symptoms vary over time in intensity and duration for each patient as well as from patient to patient. To care effectively for a lupus patient, the nurse or other health professional needs an up-to-date knowledge and understanding of the disease, its many manifestations, and its changing and often unpredictable course.

This chapter provides an overview of general and system-specific lupus manifestations and identifies potential problems. Suggested health care interventions for the nonhospitalized lupus patient are given. Many of these interventions can be modified for the hospitalized patient. The information and nursing interventions described in this chapter are not meant to be inclusive, but to provide the practitioner with guidelines for developing a care plan specific to the needs of each lupus patient.

As a care plan is developed, the health professional should keep in mind the importance of frequently reassessing the patient's status over time and adjusting treatment to accommodate the variability of systemic lupus erythematosus (SLE) manifestations. An additional and very important element of working with the lupus patient is to incorporate the patient's needs and routines in the plan of care. Adjusting nursing interventions and medical protocols to the patient's needs not only recognizes the value of the patient as an authority on her or his own illness, but also can improve patient compliance and result in an improved quality of life.

Working together, the care provider and the patient have much to offer each other. The rewards for patients and families are tremendous, as patients become more independent and gain confidence in being able to care for themselves.

Systemic Lupus Erythematosus

General Manifestations

Fatigue, fever, psychological and emotional effects

Specific Manifestations

Dermatologic: butterfly rash, photosensitivity, Discoid LE, subcutaneous LE, mucosal ulcers, alopecia, bruising

Musculoskeletal: arthralgias, arthritis, other joint complications

Hematologic: anemia, decreased white blood cell (WBC) count, thrombocytopenia, lupus anticoagulants, false-positive venereal disease research laboratory test (VDRL), elevated erythrocyte sedimentation rate (ESR), lymphopenia

Cardiopulmonary: pericarditis, myocarditis, myocardial infarction, vasculitis, pleurisy, valvular heart disease

Renal: asymptomatic microscopic renal involvement, renal failure, fluid and electrolyte imbalance, edema

Central Nervous System (CNS): cranial neuropathies, cognitive impairment, mental changes, seizures, stroke, peripheral neuropathy, meningitis, coma, psychosis

Gastrointestinal (GI): anorexia, ascites, pancreatitis, mesenteric or intestinal vasculitis

Ophthalmologic: cytoid bodies, dry eyes

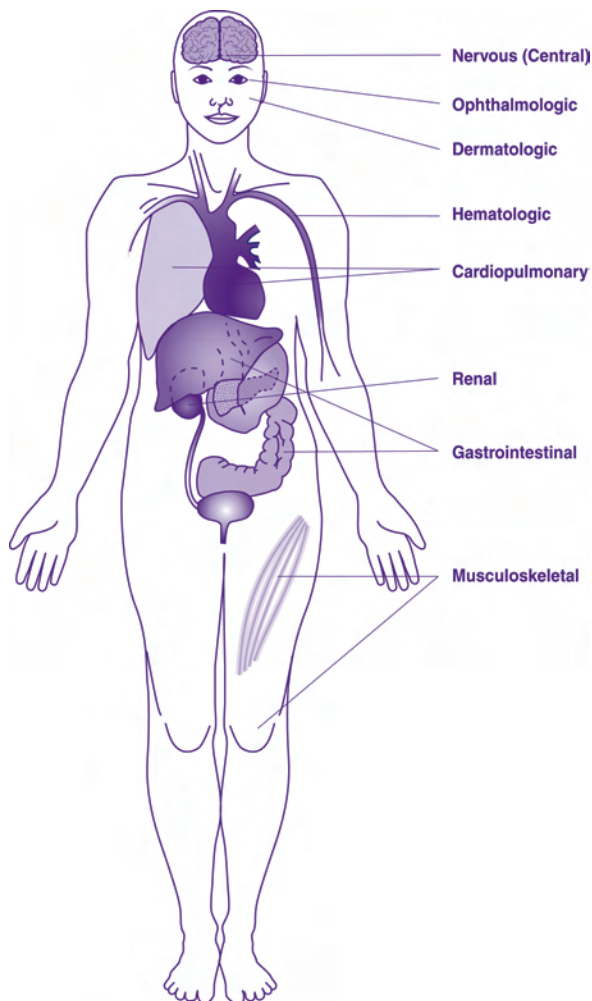
Other Key Issues

Pregnancy: lupus flare, miscarriage or stillbirth, pregnancy-induced hypertension, neonatal lupus

Infection: increased risk of respiratory tract, urinary tract, and skin infections; opportunistic infections

Nutrition: weight changes, poor diet, appetite loss

Systems Potentially Affected by Lupus



General Manifestations of SLE

Overview

Fatigue is a nearly universal complaint of patients with SLE even when no other manifestations of the disease are present. The cause of this debilitating fatigue is not known. The patient should be evaluated for factors that may exacerbate fatigue, such as hypothyroidism, adrenal dysfunction, overexertion, insomnia, depression, stress, anemia, and other inflammatory diseases. Fatigue in SLE patients may be lessened by adequate rest, healthful diet, exercise, and attention to psychosocial factors. One common cause of fatigue in SLE patients is fibromyalgia.

Many patients with SLE experience changes in weight. At least one-half of patients report weight loss before being diagnosed with SLE. Weight loss in SLE patients may be attributed to a decreased appetite, side effects of medications, GI problems, or fever. Weight gain can occur in some patients and may be due in part to prescribed medications, especially corticosteroids, or fluid retention from kidney disease.

Episodic fever is experienced by more than 80 percent of SLE patients, and there is no particular fever pattern. Although high fevers can occur during a lupus flare, low-grade fevers are more frequently seen.

A complicating infection is often the cause of an elevated temperature in a patient with SLE. The patient's WBC

count may be normal to elevated with an infection, but low with SLE alone. However, certain medications, such as immunosuppressives, will suppress the WBC count even in the presence of fever. Therefore, it is important to rule out other causes of a fever, including an infection or a drug reaction. Urinary and respiratory infections are common in SLE patients.

Some patients with SLE experience racing of the heart, or tachycardia. This rapid pulse is frequently the result of inflamed heart tissue. However, tachycardia may have other causes as well, such as an infection.



Psychological Manifestations

People with lupus often experience psychological and emotional effects, such as grief, depression, and anger. These effects can be related to outward changes, such as skin alterations caused by the disease. They can also be related to concerns about the future, and about other aspects of the disease and its treatment. It is important for health professionals to be alert to potential psychological repercussions and to assist in alleviating them.

Potential Physiological Manifestations

- fatigue
- weight gain or loss
- fever (increased temperature over normal baseline)
- tachycardia

Potential Psychological Manifestations

- depression: lowered self-esteem; negative feelings about body; feelings of decreased confidence and self-worth; feelings of sadness, hopelessness and helplessness; crying
- difficulty in completing self-care activities, caring for children, maintaining a household, and other activities of daily living
- inability to maintain full- or part-time employment
- decreased social activities
- lack of energy or ambition
- irritability
- impaired concentration
- insomnia
- suicidal thoughts

Potential Problems

1. inability to complete activities of daily living because of fatigue, weakness, and psychological difficulties
2. changes in weight
3. fever

Nursing Interventions

Objective: Minimize fatigue.

1. Assess the patient's general fatigue level.
2. Assess for the presence of depression, anxiety, and other stressors.
3. Conduct an assessment to determine the patient's daily activities that contribute to fatigue.

4. Help the patient to develop an energy-conserving plan for completing daily and other activities and work. Many people with lupus need to take a daily nap.
5. Encourage the patient to get 8 to 10 hours of sleep at night.
6. Encourage exercise as tolerated.

Objective: Maintain weight at optimal range.

1. Assess the patient's prescription and nonprescription drug regimen and dosages.
2. Assess the patient's usual daily dietary intake by asking her or him to keep a food diary.
3. Develop a dietary plan with the patient that encourages healthful eating. If the patient has nutrition-related lupus complications, refer her or him to a registered dietitian for specialized counseling.
4. Encourage exercise as tolerated.
5. Record the patient's weight at each visit.
6. Instruct the patient to weigh herself or himself at home once a week and record it.

Objective: Teach the patient to recognize fever and signs and symptoms of infection.

1. Assess the patient's prescription and nonprescription drug regimen and dosages.
2. Monitor the patient's WBC count.
3. Teach the patient to monitor temperature during a lupus flare.

4. Teach the patient to look for signs and symptoms of infection, particularly urinary and respiratory infections. (Note: The cardinal signs of infection may be masked because of corticosteroids and antipyretic medications.)
5. Instruct the patient to call a physician if signs and symptoms of an infection appear or if a fever is elevated above 101°F.

Objective: Assist the patient in adjusting to physical and lifestyle changes.

1. Allow the patient to express feelings and needs.
2. Assess the patient's usual coping mechanisms.
3. Acknowledge that feelings of denial and anger are normal.
4. Explore with the patient sources of potential support and community resources.
5. Explore possible ways of concealing skin lesions and hair loss.
6. Encourage the patient to discuss interpersonal and social conflicts that arise.
7. Encourage the patient to accept help from others, such as counseling or a support group.

Objective: Recognize the signs and symptoms of depression and initiate a plan of care.

1. Assess the patient for the major signs and symptoms of depression.

2. Assess the patient's interpersonal and social support systems.
3. Encourage the patient to express feelings.
4. Initiate a referral to a mental health counselor or psychiatrist.

For further information and nursing interventions, see the section on infection in this chapter, page 47. Also see the Patient Information Sheets in Chapter 7 on *Living With Lupus*, *Preventing Fatigue Due to Lupus*, *Skin Care and Lupus*, and *Fever and Lupus*.



Dermatologic Manifestations

Overview

Approximately 80 percent of patients with **systemic lupus erythematosus** have skin manifestations and may suffer from disfigurement. The classic sign of SLE is the “butterfly” rash extending over the cheeks (malar area) and bridge of the nose. This rash ranges from erythema to a severe eruption with scaling. It is photosensitive, and it may last several days or be fixed. Between 55 and 85 percent of patients develop this rash at some time in the course of the disease.

The most prevalent and severe form of cutaneous lupus, which affects primarily the skin, is called **chronic cutaneous lupus**. It is commonly known as discoid lupus, but has other forms as well (see below). Discoid lupus erythematosus (DLE) occurs in about 20 percent of patients with SLE. The lesions are

patchy, crusty, coin-shaped, sharply defined skin plaques that may scar. These lesions are usually seen on the face or other sun-exposed areas. DLE may cause patchy, bald areas on the scalp and hypopigmentation or hyperpigmentation in older lesions. Biopsy of a lesion will usually confirm the diagnosis. Topical and intralesional corticosteroids are often not effective, even for localized lesions. Antimalarial drugs may be needed for some local lesions and for more generalized lesions. DLE progresses to SLE in about 5 percent of cases.

Other forms of chronic cutaneous lupus include:

- *Hypertrophic or verrucous DLE* is characterized by either thickened lesions (hypertrophic) or wart-like lesions (verrucous).
- *Lupus profundus* is characterized by firm lumps in the fatty tissue underlying the skin.
- *Mucosal DLE* is characterized by lesions that occur in the mucus membranes of the mouth and nose.
- *Palmar-plantar DLE* is characterized by lesions that occur in the hands and feet.

Another form of cutaneous lupus, **subacute cutaneous LE** is seen in about 10 percent of SLE patients. It produces highly photosensitive papules or cyclic lesions. Skin changes, especially the butterfly rash and the effects of subacute cutaneous LE, can be precipitated by sunlight.

Some patients may develop mouth, vaginal, or nasal ulcers. Hair loss (alopecia) occurs in about one-half of SLE patients. Most hair loss is diffuse, but it may be patchy. It can be scarring or non-scarring. Alopecia may also be caused by corticosteroids, infection, or immunosuppressive drugs.

Raynaud's phenomenon (episodic blanching of the fingers and toes due to paroxysmal vasospasm) frequently occurs in patients with SLE. For most patients, Raynaud's phenomenon is mild. However, some SLE patients with severe Raynaud's phenomenon may develop painful skin ulcers or gangrene on the fingers or toes. Attacks of Raynaud's phenomenon can cause a deep tingling feeling in the hands and feet that can be very uncomfortable.

Skin alterations in the lupus patient, particularly those of DLE, can be disfiguring. As a result, patients may experience fear of rejection by others, negative feelings about their body, and depression. Changes in lifestyle and social involvement may occur.

Potential Problems

1. alteration in skin integrity
2. alopecia
3. discomfort (pain, itching)
4. alteration in body image
5. depression

Potential Dermatologic Manifestations

- butterfly rash on cheeks and bridge of nose
- scaly, disk-shaped scarring rash (DLE)
- erythematous, slightly scaly papules (subacute cutaneous LE)
- psoriasiform or arcuate (curved) lesions on the trunk of the body (subacute cutaneous LE)
- ulcers in the mouth, vagina, or nasal septum
- atrophy (including striae or stretch marks from corticosteroids)
- impaired wound healing
- easy bruising
- petechiae
- increased body hair (hirsutism) from corticosteroids
- steroid-induced ecchymosis
- ulcers or gangrene on fingers or toes
- alopecia
- redness in the nail bed (periungual erythema)
- a reddish or cyanotic pattern seen on arms, legs, or torso, especially in cold weather (livedo reticularis)

Nursing Interventions

Objective: Minimize appearance of lesions.

1. Document the appearance and duration of lesions and rashes.
2. Teach the patient to minimize direct exposure to UV rays from sun and from fluorescent and halogen light bulbs. (Glass does not provide complete protection from UV rays.)
3. Instruct the patient to use a sunscreen with an SPF of 15 or greater and wear protective clothing. Patients who are allergic to PABA will need to find a PABA-free sunscreen.
4. Provide information on hypoallergenic concealing makeup.
5. Instruct the patient to avoid topical applications, such as hair dyes and skin creams, and the use of certain drugs that may make her or him more sensitive to the sun.

Objective: Alleviate discomfort.

1. For patients with mouth lesions, suggest a soft-food diet, lip balms, and warm saline rinses.
2. Ask the physician to consider prescribing Kenalog® in Orabase®, which is applied twice a day to oral ulcers.
3. Suggested self-help measures for patients with Raynaud's phenomenon include:
 - keep warm, particularly in cold weather; use chemical warmers, gloves, socks, hats; avoid air conditioning; use

insulated drinking glasses for cold drinks; wear gloves when handling frozen or refrigerated foods

- quit smoking
- control stress
- exercise as tolerated.

Objective: Help patients to cope with potential psychological manifestations.

1. See the nursing interventions dealing with psychological issues under manifestations on pages 29–30.



Musculoskeletal Manifestations

Overview

Arthralgia or arthritis is experienced by 95 percent of SLE patients at some time during the course of the disease. Articular pain is the initial symptom in about one-half of patients eventually diagnosed with SLE. Morning stiffness and joint and muscle aching can also occur. Joint pain may be migratory; it is typically symmetric but is asymmetric in many patients. Joints may become warm and swollen. X rays of the joints usually do not show erosion or destruction of bone.

Proliferation of the synovium in lupus is more limited than in rheumatoid arthritis, and joint destruction is rare. The joints most commonly involved are those of the fingers, wrists, and knees; less commonly involved are the elbows, ankles, and shoulders.

Several joint complications may occur in SLE patients, including reducible deformities such as Jaccoud's arthropathy and osteonecrosis. In SLE patients, osteonecrosis may develop as a steroid complication, which causes bone death in the hips or other joints. Subcutaneous nodules are rarely seen. Tendinitis and carpal tunnel syndrome are seen occasionally. Tendon rupture is very rare.

Potential Problems

1. pain
2. alteration in joint function

Nursing Interventions

Objective: Minimize pain from joint and muscle complications.

1. Assess and document joint complaints and appearance. Changes may be transient.
2. Assess the patient's self-management techniques for controlling pain.
3. Teach the patient to apply heat or cold as appropriate.
4. Instruct the patient in use of prescription and nonprescription pain medications.
5. Teach the patient to apply splints or braces, if ordered by physician.

Potential Musculoskeletal Manifestations

- morning stiffness and aching
- joint pain
- warm, swollen joints
- rarely, ulnar deviation of the fingers with swan neck deformities and subluxations

Generalized myalgia and muscle tenderness, especially over the shoulders, is more likely to be fibromyalgia than lupus.

Objective: Maintain joint function and increase muscle strength.

1. Suggest warm showers or baths to lessen stiffness and pain.
2. If indicated, refer patients with acutely inflamed joints to a physical therapist for passive range-of-motion (ROM) exercises. The physical therapist may train a family member to assist the patient with ROM exercises at home.
3. Teach the patient that an inflamed joint should not bear weight and suggest that the patient avoid strenuous activity.
4. If needed, assist the patient in obtaining crutches, a walker, or a cane.



Hematologic Manifestations

Overview

Abnormal blood conditions are common in patients with SLE. Problems include anemia, leukopenia, thrombocytopenia, and other clotting disorders.

Anemia, which is common in SLE patients, reflects insufficient bone marrow activity, shortened red blood cell (RBC) life span, or poor iron uptake. Aspirin, NSAIDs, and prednisone can cause stomach bleeding and exacerbate the condition. Iron deficiency is treated by iron supplementation. Immune-mediated anemia (or hemolytic anemia), which is due to antibodies directed at RBCs, is treated with corticosteroids.

Leukopenia, which is also relatively common in SLE patients, may be more severe with flares of the disease or with the use of immunosuppressive drugs. In severe cases, low WBC counts can increase the risk of infections.

Thrombocytopenia may occur and – if it is mild – may respond to low-dose corticosteroids. Mild forms may not need to be treated, but a severe form requires high-dose corticosteroid or cytotoxic drugs. The major clinical features of antiphospholipid antibodies (APLs) and antiphospholipid syndrome are venous thrombosis, arterial thrombosis, pregnancy loss or thrombocytopenia with a history of positive anticardiolipin antibody, anti- β_2 glycoprotein I, or lupus anticoagulant tests.

Abnormal laboratory tests may include a false-positive VDRL test for syphilis. Fluorescent treponemal antibody absorption (FTA-ABS) and microhemagglutination-*Treponema pallidum* (MHA-TP) tests, which are more specific tests for syphilis, are almost always negative if the patient does not have syphilis. An elevated erythrocyte sedimentation rate (ESR) is a common finding in SLE, but it does not mirror disease activity.

Potential Problems

1. inability to complete activities of daily living because of fatigue and weakness
2. anemia
3. potential for hemorrhage
4. potential to develop venous or arterial thromboses
5. increased risk of infection

Nursing Interventions

Objective: Minimize fatigue.

Refer to the nursing interventions for fatigue on pages 29–30.

Objective: Recognize anemia and develop a plan of care.

1. Monitor the patient for signs and symptoms of anemia and for altered laboratory values.
2. Develop a plan with the patient to conserve energy.
3. Teach the patient the basics of good nutrition.
4. Instruct the patient to take iron preparation medications as prescribed.

Potential Hematologic Manifestations

Anemia

- decreased hemoglobin and hematocrit values
- positive Coombs' test (hemolytic anemia)
- dizziness
- sensitivity to cold
- chronic fatigue, lethargy, and malaise
- pallor
- weakness
- dyspnea on exertion
- headache

Leukopenia

- increased risk of infection
- usually not associated with symptoms

Thrombocytopenia

- petechiae
- excessive bruising of skin
- bleeding from gums, nose
- blood in stool

Objective: Minimize episodes of bleeding.

1. Assess the patient for signs and symptoms of bleeding, such as petechiae, bruises, GI bleeding, blood in urine, ecchymoses, nose bleeds, bleeding from the gums, heavy menses, and bleeding between menstrual periods.
2. Teach the patient why she or he is at risk of bleeding (low platelet count, anemia, thrombocytopenia) and to report episodes to physician.

3. Encourage the patient to wear a medical alert bracelet or carry a card.
4. Teach the patient measures to prevent bleeding, such as use of a soft toothbrush or an electric shaver.

Objective: Decrease risk of infection.

See the nursing interventions for infection on page 48.

Note: For more information, see *Laboratory Tests Used to Diagnose and Evaluate SLE* (Chapter 3) and the Patient Information Sheet in Chapter 7 on *Preventing Fatigue Due to Lupus*.



Cardiopulmonary Manifestations

Overview

Cardiac abnormalities contribute significantly to morbidity and mortality in SLE and are among the most important clinical manifestations of the disease. In addition, involvement of the lungs and pleurae is common. Pericarditis, an inflammation of the pericardium, is the most common cardiac abnormality in SLE. Myocarditis, an inflammation of the heart muscle, may also occur, but is rare. Myocardial infarction, caused by atherosclerosis, is increased in SLE patients, even below the age of 35 years.

Pleuritic chest pain is common. Pleurisy is the most common respiratory manifestation in SLE. Attacks of pleuritic pain can also be associated with pleural effusions. Many patients complain of chest pain, but pericardial changes are not often demonstrated on clinical evaluation.

Potential Problems

1. alterations in cardiac function
2. potential for impaired gas exchange and ineffective breathing patterns
3. alteration in tissue perfusion

Potential Cardiopulmonary Manifestations

Pericarditis

- pain in the anterior chest, neck, back, or arms that is often relieved by sitting up
- shortness of breath
- swelling of legs and feet
- audible pericardial friction rub

Myocarditis

- shortness of breath
- fatigue
- palpitations

Atherosclerosis Leading to Myocardial Infarction

Warning signs of myocardial infarction include:

- burning, choking, squeezing, or pressing chest pain that may radiate to left shoulder and arm
- shortness of breath
- weakness
- unrelieved indigestion
- nausea and vomiting

Pleurisy

- shortness of breath
- chest pain, especially with deep inspiration

Leukocytoclastic Vasculitis

- necrotic ulcerations, including raised hemorrhagic nodules (papule, purpura) that ulcerate, especially on the lower legs, ankles, and dorsa of the feet

Valvular Heart Disease (Libman-Sacks Lesions)

- lesions that may result in cardiac murmurs and valve dysfunction; associated with APLs

Venous Thrombosis

- positive Homans' sign (pain associated with forced dorsiflexion of the ankle)
- pain, swelling, inflammation, redness, and warmth in the affected limb
- increased circumference of affected limb

Arterial Thrombosis

- pain or loss of sensation due to ischemia in an extremity
- paresthesias and loss of position sense
- coldness
- pallor
- paralysis, loss of speech
- no pulse in the extremity

Nursing Interventions

Objective: Detect changes in cardiac function.

1. Assess the patient for signs and symptoms of potential cardiac problems.
2. Teach the patient signs and symptoms of cardiac problems, including warning signs of a heart attack; reinforce the importance of reporting them to the physician.
3. Educate the patient about medications.
4. Educate the patient about a healthful diet and regular exercise as tolerated.

Objective: Maintain adequate gas exchange and effective breathing patterns.

1. Assess quality and depth of respirations; auscultate breath sounds.
2. Suggest measures to relieve pain, such as relaxation techniques, biofeedback, rest, and pain medications as ordered.
3. Encourage patients who smoke to quit.

Objective: Ensure adequate tissue perfusion.

1. Assess skin color and temperature; check for lesions.
2. Check capillary refill in the nailbeds.
3. Assess for presence of edema and pain in the extremities.
4. Stress the importance of not smoking.
5. Teach the patient the basics of good foot care.
6. Teach the patient to avoid cold temperatures and to keep the hands and feet warm, especially in winter months.
7. Teach the patient the signs and symptoms of vascular impairment that need to be reported to the physician, including a change in skin color or sensation or appearance of lesions.

Objective: Recognize the signs and symptoms of thromboses; refer for immediate medical attention.

1. Teach the patient the signs and symptoms of potential venous or arterial thrombosis and reinforce the need to contact a physician immediately.

Note: For additional information, see the Patient Information Sheet in Chapter 7 on *Serious Conditions Associated With Lupus*.



Renal Manifestations

Overview

Renal damage is one of the most serious complications of SLE. The majority of people with lupus have some degree of asymptomatic microscopic kidney damage. Fifty percent have clinical renal disease. Kidney damage may necessitate treatment with corticosteroids, cytotoxic agents, dialysis, or renal transplantation.

Renal biopsy can be helpful in making decisions about drug treatments and determining prognosis by assessing the presence of active renal disease versus scarring.

Potential Problems

1. impaired renal function
2. fluid and electrolyte imbalance

Potential Renal Manifestations

SLE Nephropathy Signs and Symptoms:

- hematuria (as few as 5 RBCs is significant)
- proteinuria (>1+)
- sterile pyuria
- elevated creatinine level (indicates loss of renal function)
- elevated blood urea nitrogen (BUN)
- weight gain
- ankle edema
- hypertension

Signs and Symptoms Suggesting Renal Failure

- nausea and vomiting
- anorexia
- anemia
- lethargy
- pruritus
- changing level of consciousness

Fluid and Electrolyte Imbalance (Excess Extracellular Fluid Volume)

- weight gain
- pitting edema of the lower extremities
- sacral edema
- bounding pulse, elevated blood pressure, S3 gallop
- engorgement of neck and hand veins
- dyspnea
- crackles in lungs
- cyanosis
- decreased hematocrit
- urine specific gravity <1.010
- variable serum sodium level (normal, high, or low), depending on the amount of sodium retention or water retention
- serum osmolality <275 mOsm/kg

Nursing Interventions

Objective: Promptly recognize renal involvement and prevent complications.

1. Document any patient complaints or assessment findings that may indicate renal involvement.
2. Teach the patient to watch for signs and symptoms of renal complications and report them promptly to the physician: facial swelling, peripheral edema, “foamy” urine (proteinuria), “coke-colored” urine (hematuria), or nocturia and urinary frequency.
3. Assess the patient for early signs of heart failure.
4. Refer the patient to a dietitian for counseling on dietary changes to accommodate alterations in renal status.
5. Teach the patient to take prescribed medications as ordered.
6. Stress the importance of referral and followup care with nephrologist if necessary.

Objective: Decrease fluid retention and edema.

1. Monitor electrolyte values.
2. Assess breath sounds and instruct the patient to report shortness of breath or dyspnea.
3. Teach the patient to maintain balanced fluid intake and output.
4. Monitor the patient for signs and symptoms of extracellular fluid overload.
5. Instruct the patient to weigh herself or himself daily to monitor fluid retention.
6. Monitor the patient's blood pressure and teach the patient how to monitor it at home.

Objective: Minimize risk of infection.

1. Teach the patient to watch for the signs and symptoms of urinary tract infection and to report them to the physician.
2. Instruct the patient that corticosteroid therapy may mask the usual symptoms of infection and that she or he may have an altered immune response because of medications used to control SLE.
3. Teach the patient to take antibiotics for urinary tract infection as prescribed.

Note: For additional information, see the Patient Information Sheet in Chapter 7 on *Serious Conditions Associated With Lupus*.



Central Nervous System Manifestations

Overview

Neurologic manifestations of SLE are common and vary from mild to severe. They can be difficult to diagnose and distinguish from other diseases. All portions of the nervous system may be affected, including the CNS. Definite diagnosis of CNS lupus may be difficult, as symptoms may be related to medications, other medical conditions, or individual reactions to chronic illness.

Examples of neurological manifestations include cranial or peripheral neuropathy, psychosis, coma, transverse myelitis, meningitis, cognitive impairment, mental changes, seizures, and stroke.

Cranial or peripheral neuropathy occurs in 10 to 15 percent of patients; it is probably secondary to vasculitis in small arteries supplying nerves. Cerebrovascular accidents (strokes) are reported in approximately 15 percent of patients. Between 10 and 20 percent of patients experience seizures. Although cognitive impairment is believed to be very common, formal cognitive function testing may be required in order to document it.

Serious CNS involvement ranks behind only kidney disease and infection as a leading cause of death in lupus. However, the majority of SLE patients with CNS complications do not develop a life-threatening disease.

Potential CNS Manifestations

General CNS lupus

- headaches¹
- confusion
- seizures
- psychosis
- numbness
- paralysis
- coma
- aphasia

Cranial neuropathies

- visual defects
- blindness
- nystagmus (involuntary movement of the eyeball)
- ptosis (paralytic drooping of the eyelid)
- papilledema (edema in the optic disk)
- tinnitus
- vertigo
- facial palsy

Spine

- transverse myelitis

Cognitive impairment

- confusion
- impaired long- and short-term memory
- difficulty in conceptualizing, abstracting, generalizing, organizing, and planning information for problem solving
- difficulties in personal orientation and in dealing with the larger world
- selective attention
- difficulties in pattern recognition, sound discrimination and analysis, and visual-motor integration

Mental changes

- depression
- anxiety
- affective disorder
- mood swings
- hypomania or mania (especially with corticosteroid use)

Rare CNS manifestations

- myelitis
- movement disorder

¹ Although headaches are not usually due directly to lupus, an unusual, new, severe headache requires evaluation.

Potential Problems

1. alteration in mental status, cognition, and perception
2. altered ability to perform activities of daily living and meet family responsibilities
3. potential for injury

Nursing Interventions

Objective: Develop a plan for the patient to perform activities of daily living appropriately and independently.

1. Assess and document the patient's mental status to determine her or his capabilities:
 - general appearance
 - unusual body movements
 - speech patterns and word use
 - alertness and orientation to time, place, and person
 - memory of remote and recent past
 - perception of self and environment

- affect and emotional stability
 - ability to solve problems
 - presence of depression.
2. Support the patient's need to maintain some control over daily activities and decisions:
 - Encourage the patient to plan and participate in daily routines.
 - Set aside time to develop trust and rapport with the patient, and be consistently truthful (patients are keenly aware of inconsistencies in information provided).
 3. Encourage the patient to discuss the effects of SLE on her or his personal life and coping methods. Allow expressions of fear and anger.

Objective: Assist the patient in identifying family and community support services.

1. Assess the patient's support network. Discuss alternatives for strengthening supports.
2. Anticipate family concerns. Seek out family members to answer their questions and to provide support. Include significant others in patient care as appropriate.
3. Help the family identify potential coping skills, environmental supports, and community services for dealing with chronically ill people.
4. Encourage patient and family members to consider professional counseling.

Objective: Minimize potential for injury.

1. Assist the patient and family in identifying and removing potentially dangerous items in the environment.
2. Involve family members in planning the patient's care and safety measures.
3. Assess the patient's ability to safely administer her or his own medications.

Note: For additional information, see the Patient Information Sheets in Chapter 7 on *Living With Lupus and Serious Conditions Associated With Lupus*.



Gastrointestinal Manifestations

Overview

Gastrointestinal (GI) problems are common and range from vague complaints of anorexia to life-threatening bowel perforation secondary to mesenteric arteritis. Anorexia, nausea, vomiting, and diarrhea may be related to the use of salicylates, NSAIDs, antimalarials, corticosteroids, and cytotoxic drugs.

SLE patients who present with acute abdominal pain, esophageal dysmotility, and tenderness need immediate, aggressive, and comprehensive evaluation to rule out an intra-abdominal crisis. Ascites, an abnormal accumulation of fluid in the peritoneal cavity, is rare. Pancreatitis is a serious complication occurring in approximately 5 percent of SLE patients and is usually secondary to vasculitis.

Mesenteric or intestinal vasculitis is a life-threatening condition that may have

complications of obstruction, perforation, or infarction. It is rare. Abnormal liver enzyme levels are also found in about one-third of SLE patients, and can be from lupus, infection, or medication.

Potential GI Manifestations

General manifestations

- dry mouth (characteristic of patients with coexisting Sjögren's syndrome)
- anorexia
- nausea and vomiting
- diarrhea
- dysphagia (especially in association with Raynaud's phenomenon)

Pancreatitis

- mild nonspecific abdominal pain to severe epigastric pain radiating to the back
- nausea
- vomiting
- elevated serum amylase level
- dehydration

Ascites

- abdominal distention
- bulging flanks
- downward protruding umbilicus

Mesenteric and intestinal vasculitis

- cramping or constant abdominal pain
- vomiting
- fever
- diffuse direct and rebound abdominal tenderness

Nutritional Deficiencies

- See pages 49–50 for signs and symptoms of nutritional deficiencies.

Potential Problems

1. alteration in GI function related to drug therapy or disease process
2. nutritional deficiencies

Nursing Interventions

Objective: Minimize GI side effects caused by medications.

1. See Chapter 5, *Medications Used to Treat Lupus* and the Patient Information Sheets in Chapter 7 on *Nonsteroidal Anti-Inflammatory Drugs, Antimalarials, Corticosteroids, Azathioprine, Cyclophosphamide, Methotrexate, Cyclosporine, Mycophenolate Mofetil, and Intravenous Immunoglobulins.*

Objective: Minimize complications from GI manifestations.

1. Assess the patient for GI problems at each visit.
2. Monitor laboratory results.
3. Suggest measures that may increase comfort, such as throat lozenges, saline rinses, or small, frequent meals.
4. Instruct the patient to report immediately any sudden or severe abdominal pain, shortness of breath, or epigastric pain to physician.
5. Refer the patient to dietitian.

Objective: Maintain nutritional status.

1. See the nursing interventions under the nutrition section of this chapter on pages 49–50 and the Patient Information Sheet in Chapter 7 on *Nutrition and Lupus.*

Ophthalmologic Manifestations

Overview

Eye disease occurs in approximately 20 percent of patients with SLE. In some cases, eye problems are related to the inflammatory process of lupus itself. In other cases problems may be due to drug treatment (corticosteroids or antimalarials) or may be a separate problem (glaucoma or retinal detachment). Blindness due to SLE occurs, but is rare.

The following eye problems occur in lupus:

- A lupus rash may develop on the eyelids.
- Kerato-conjunctivitis is “dry eye” related to Sjögren’s syndrome. Some people with lupus have Sjögren’s syndrome, which is an autoimmune condition that causes excessive dryness of the mucous membranes. People with lupus who have these symptoms require artificial tears to relieve dry eyes.
- Uveitis (inflammation of the iris, ciliary body, vitreous gel and/or choroid) and scleritis may be part of the systemic inflammatory process of the disease.
- Cytoid bodies are the most common retinal change in SLE. They reflect microangiopathy of the retinal capillaries and localized microinfarction of the

superficial nerve fiber layers of the retina.

- Glaucoma and cataracts may be caused by corticosteroids.
- Antimalarials can damage the retina, which can impair vision (particularly color vision) or, extremely rarely, cause blindness. The risk of retinopathy is as low as 1 in 5,000.

Potential Problems

1. discomfort
2. visual impairment
3. potential for injury
4. difficulty carrying out activities of daily living

Nursing Interventions

Objective: Minimize discomfort.

1. Allow time for the patient to express concerns and ask questions.
2. Teach the patient how to apply artificial tears for dry eyes to increase comfort and prevent corneal abrasion.
3. Teach the patient the correct way to take prescribed medications, such as eye drops for glaucoma.

Objective: Minimize potential for serious visual impairment or blindness.

1. Assess the patient’s vision changes and impairments.
2. Reinforce the need to follow up with an ophthalmologist.

Potential Ophthalmologic Manifestations

- a lupus rash on the eyelids
- red eyes
- loss of tears, dry eyes
- mucus discharge from eyes, particularly upon awakening
- sensitivity to light
- change in vision
- blurred vision
- cloudy lens(es)
- burning sensation in eyes

Objective: Develop a plan for patient to perform activities of daily living appropriately and independently.

1. Provide referrals to support groups and services for the visually impaired.
2. Refer to the CNS lupus nursing interventions on pages 41–42 for additional suggestions.

Objective: Minimize potential for injury.

1. See the CNS lupus nursing interventions on pages 41–42 for suggestions.

Note: For additional information, see the Patient Information Sheets in Chapter 7 on *Living With Lupus and Serious Conditions Associated With Lupus*.



Pregnancy

Overview

Twenty-five years ago, women with lupus were counseled not to become pregnant because of the risk of a flare of the disease and an increased risk of miscarriage. Research and careful treatment have made it possible for more and more women with lupus to have successful pregnancies. Although a lupus pregnancy is still considered high risk, most women with lupus are able to carry their babies safely to term. Experts disagree on the exact numbers, but approximately 10 percent of lupus pregnancies end in miscarriage. Pregnancy counseling and planning before pregnancy are important. Optimally, a woman should have no signs or symptoms of lupus before she becomes pregnant.

Researchers have identified two closely related lupus autoantibodies, anticardiolipin antibody and lupus anticoagulant, that are associated with risk of miscarriage. One-third to one-half of women with lupus have these autoantibodies, which can be detected by blood tests. Identifying women with the autoantibodies early in the pregnancy may help physicians take steps to reduce the risk of miscarriage. Pregnant women who test positive for these autoantibodies and who have had previous miscarriages are generally treated with baby aspirin and heparin throughout their pregnancy.

While it used to be said that flares, if they occurred, were more frequent postpartum, they can in fact occur

during any trimester as well. Some women may experience a mild to moderate flare during or after their pregnancy; others may not. Pregnant women with lupus, especially those taking corticosteroids, are also likely to develop pregnancy-induced hypertension, diabetes, hyperglycemia, and kidney complications. About 25 percent of babies of women with lupus are born prematurely, but do not suffer from birth defects. If a patient has not been on glucocorticoids during pregnancy, there is no reason to initiate these medications to prevent a postpartum flare.

In rare cases, babies may be born with a condition called neonatal lupus. This condition causes the fetus or neonate to develop problems in the heart, skin, liver, and/or blood. Neonatal lupus is not the same as SLE. It is associated with maternal antibodies called anti-Ro(SSA) and anti-La(SSB). Neonatal lupus can be identified in utero between 18 and 24 weeks. The most common manifestations are heart block (heart beats abnormally slowly) or a rash, most often seen around the eyes.

- The heart block is almost always permanent, and most children will need pacemakers for life.
- The skin rash can appear at birth, but most commonly presents at about 6 weeks after birth. This condition is transient and disappears by about 8 months.
- The liver and blood problems are also transient.

The risks of having a child with heart block for a mother with anti-Ro(SSA) and anti-La(SSB) antibodies are as follows:

- For first-time mothers or mothers who have had only healthy babies: 2 percent.
- For mothers who have previously given birth to a child with heart block: 18 percent.

Potential Problems

1. lupus flare
2. increased risk of spontaneous abortion or stillbirth
3. pregnancy-induced hypertension
4. increased risk of prematurity
5. neonatal lupus

Nursing Interventions

Objective: Educate the woman regarding birth control options and risks of pregnancy.

1. Encourage patient to plan pregnancy during remission and only after consulting with her doctor.
2. Discuss birth control options:
 - Barrier methods (diaphragm or condom with spermicidal foam) are the safest.
 - Intrauterine devices (IUD) should be considered for people with lupus on a case-by-case basis. Women on immunosuppressive drugs in particular may be at increased risk of infections from IUDs. Women with thrombocytopenia may have an increased risk of bleeding.

Potential Lupus Complications During Pregnancy

Lupus flare

- morning stiffness and swollen joints
- fever
- development or worsening of a rash

Miscarriage

- cramping
- vaginal bleeding (spotting to heavy bleeding)

Pregnancy-induced hypertension

- blood pressure 140/90 and over during the second half of pregnancy
- generalized edema
- proteinuria

Pre-eclampsia

- blood pressure 140/90 and over during the second half of pregnancy
- proteinuria
- epigastric pain
- hyperreflexia
- edema, including face and hands
- headache

Eclampsia

- all of the symptoms of pre-eclampsia
- seizures

Neonatal lupus

- transient rash
- transient blood count abnormalities
- heartblock

- Oral contraceptives may be appropriate if there are no APLs.
3. Discuss the potential risks of pregnancy and the importance of careful monitoring.

Objective: Ensure a healthy, full-term pregnancy.

1. Urge patient to keep appointments with her primary doctor and obstetrician.
2. Instruct patient to observe for signs of complications or an impending flare.
3. Monitor blood pressure and watch for signs of toxemia, which may be hard to distinguish from a lupus kidney flare.

Note: For additional information, see the Patient Information Sheet in Chapter 7 on *Pregnancy and Lupus*.



Infection

Overview

SLE affects the immune system, thus reducing the body's ability to prevent and fight infection. In addition, many of the drugs used to treat SLE also suppress the function of the immune system, thereby further depressing the ability to fight infection. The risk of infection parallels medication dosages and duration of treatment.

Patients with SLE who show signs and symptoms of infection need prompt therapy to prevent it from becoming life threatening. The most common infections involve the respiratory

tract, urinary tract, and skin and do not require hospitalization if they are treated promptly. Other opportunistic infections, particularly *Salmonella*, herpes zoster, and *Candida* infections, are more common in patients with SLE because of altered immune status.

Potential Manifestations of Infection

Respiratory tract infections

- sore throat
- sneezing
- fever
- productive or nonproductive cough
- runny nose
- malaise
- chills
- back and muscle pain
- dyspnea
- wheezing or rales
- nausea
- vomiting

Urinary tract infections

- chills
- fever
- flank pain
- nausea
- vomiting
- urinary frequency
- dysuria
- hematuria

Skin infections

- lesions
- redness
- swelling
- tenderness or pain

Potential Problems

1. Increased risk of infection

Nursing Interventions

Objective: Minimize incidence of infection.

1. Assess the patient's current medications, particularly those that promote susceptibility to infection such as corticosteroids and immunosuppressives.
2. Teach the patient to use good hand-washing and personal-hygiene techniques.
3. Teach the patient the signs and symptoms of infection and reinforce the importance of reporting them to the physician.
4. Encourage the patient to eat a balanced diet with adequate calories to help preserve the immune system.
5. Teach the patient to minimize exposure to crowds and people with infections or contagious illnesses.

Objective: Educate the patient about immunizations.

1. Check the patient's current immunization status.
2. Teach the patient that infections can be minimized with immunizations.
3. Encourage the patient to consult her or his doctor before considering allergy shots or flu or pneumococcal vaccines; these medications may induce a lupus flare.

Note: For additional information, see the section on general manifestations of SLE in this chapter, pages 28–31. Also see the Patient Information Sheet in Chapter 7 on *Fever and Lupus*.



Nutrition

Overview

The patient with lupus often has special nutritional needs related to medical conditions that may arise during the course of the disease. These conditions include steroid-induced osteoporosis or diabetes, cardiovascular disease, and kidney disease. For the SLE patient to maintain optimal health, the nurse must work closely with the patient, dietitian, and physician to develop a nutritional plan specific to the patient's disease and manifestations.

Potential Manifestations of Nutritional Problems

- weight loss or gain
- loss of interest in food
- anorexia
- dry, rough, scaly skin
- dull, dry, brittle, thin hair
- loss of lean muscle mass
- listlessness, apathy
- poor muscle tone
- constipation or diarrhea
- irritability
- fatigue and lack of energy
- inflamed or bleeding gums

Potential Problems

1. weight changes
2. anorexia
3. alteration in nutritional status due to drug therapy or complications of SLE

Nursing Interventions

Objective: Determine the causes of the patient's altered nutritional status.

1. Conduct a physical assessment of the patient, including weight, height, and percentage of body fat.
2. Assess the patient's nutritional intake by asking her or him to keep a food diary.
3. Assess the patient's current medications and doses.
4. Determine dietary and nutrient intake and vitamin/mineral supplement intake, food sensitivities (allergies may provoke a flare), food preferences, and experience with fad diets to "cure" lupus.
5. Assess the patient for signs and symptoms of SLE-associated conditions, including osteoporosis, diabetes, and cardiovascular and kidney disease.
6. Monitor laboratory values such as hemoglobin, hematocrit, serum ferritin, serum iron, total cholesterol, HDL, LDL, VLDL, triglycerides, and plasma protein levels.
7. Assess the patient for signs and symptoms of depression.
8. Assess the patient's knowledge of nutrition and understanding of a healthful diet.
9. Assess the patient's ability to purchase and prepare meals.
10. Assess the patient's activity level.

11. Assess the cultural, socioeconomic, and religious factors that may influence the patient's diet.

Objective: Educate patient about healthful eating to prevent alteration in nutritional status.

1. Encourage the patient to maintain a healthful diet, and discuss nutritional claims of “curing lupus,” which are often misleading.
2. Provide the patient with information on the basics of a well-balanced diet and its importance in a chronic disease such as lupus.
3. Instruct the patient to take iron supplements only if iron stores are depleted.
4. Suggest vitamin and mineral supplementation, if necessary.
5. Refer the patient to dietitian for assistance in dietary planning for serious conditions associated with SLE.

Note: For additional information, see the Patient Information Sheet in Chapter 7 on *Nutrition and Lupus*.

Chapter 5

Medications Used to
Treat Lupus



Medications are important for managing many systemic lupus erythematosus (SLE) patients. An array of drug therapies is now available, and this has increased the potential for effective treatment and excellent patient outcomes. Once a person has been diagnosed with lupus, the doctor will develop a treatment plan based on the person's age, health, symptoms, and lifestyle. It should be reevaluated regularly and revised as necessary to ensure that it is as effective as possible. The goals for treating a patient with lupus include:

- reducing tissue inflammation caused by the disease
- suppressing immune system abnormalities that are responsible for tissue inflammation
- preventing flares and treating them when they do occur
- easing symptoms such as joint pain and fatigue
- minimizing complications of the disease.



Patients and Providers: Working Together

People with lupus should work with their doctors to develop their medication treatment plan. Patients should thoroughly understand the reason for taking a drug, its action, dose, administration times, and common side effects. Pharmacists also can be a good resource for patients by helping them understand their medication treatment plan. If a patient experiences a problem believed to be related to a medication, the patient should notify her or his doctor immediately. It can be dangerous to suddenly stop taking some medications, and patients should not stop or change treatments without first talking to their doctor.

The array of drugs and the complexity of treatment plans can be overwhelming and confusing. Newly diagnosed patients and patients whose treatment plans have changed should be closely followed and have immediate access to a nurse or doctor if they are having problems with the prescribed medications. Most SLE patients do well on lupus medications and experience few side effects. Those who do experience negative side effects should not become discouraged, because alternative drugs are often available.

Health professionals should review drug treatment plans with the lupus patient at each office visit to determine

her or his understanding of and compliance with the plan. Questions should be encouraged and additional teaching done to reinforce or provide additional information as needed.

It is important to note that people with lupus often require drugs for the treatment of conditions commonly seen with the disease. Examples of these types of medications include diuretics, antihypertensives, anticonvulsants, cholesterol-lowering drugs, and antibiotics. Vaccinations are important to prevent diseases that could present a particular danger to people with lupus; however, live vaccines are not advised for people with lupus who are taking immunosuppressive drugs.

This chapter describes some of the main drugs used to treat SLE. The information presented is intended as a brief review and reference. Drug references and other medical and nursing texts provide more complete and detailed information regarding the use of each drug and the associated nursing care responsibilities.



Educating Patients About Lupus Medications

Chapter 7 contains a Patient Information Sheet on each category of lupus medication covered here. The sheets can be used to teach people with lupus about the medications they may need to take. Each sheet contains general information about the category of drug,

specific instructions on how and when to take the specific medication prescribed, information about possible side effects, and precautions.*



Nonsteroidal Anti-Inflammatory Drugs (NSAIDs)

The NSAIDs comprise a large and chemically diverse group of drugs that possess analgesic, anti-inflammatory, and antipyretic properties. Pain and inflammation are common problems in patients with SLE, and NSAIDs are usually the drugs of choice for patients with mild SLE and little or no organ involvement. Patients with serious organ involvement may require more potent anti-inflammatory and immunosuppressive drugs.

Types of NSAIDS

There are more than two dozen different NSAIDs on the market, and many new ones are in development. Some can be purchased as over-the-counter preparations, whereas larger doses of those drugs or other preparations are available only by prescription. For example, prescriptions are required for diclofenac sodium (Voltaren®), indomethacin (Indocin®), diflunisal (Dolobid®), and nabumetone (Relafen®).

*Brand names included in this book are provided as examples only; their inclusion does not mean that these products are endorsed by NIH or any other Government agency. Also, if a particular brand name is not mentioned, this does not mean or imply that the product is unsatisfactory.

Mechanism of Action and Use

The therapeutic effects of NSAIDs stem from their ability to inhibit the release of prostaglandins and leukotrienes, which are responsible for producing inflammation and pain. NSAIDs are very useful in treating joint pain and swelling, as well as muscle pain. They may also be used to treat pleuritic chest pain. An NSAID may be the only drug needed to treat a mild flare; more active disease may require additional medications.

Although all NSAIDs appear to work in the same way, not every one has the same effect on every person. In addition, patients may do well on one NSAID for a period of time, then, for some unknown reason, derive no benefit from it. Switching the patient to a different NSAID should produce the desired effects. Patients should use only one NSAID at any given time.

Side/Adverse Effects

Gastrointestinal (GI): dyspepsia, heartburn, epigastric distress, and nausea; less frequently, vomiting, anorexia, abdominal pain, GI bleeding, and mucosal lesions. Misoprostol (Cytotec®), a synthetic prostaglandin that inhibits gastric acid secretion, may be given to prevent GI intolerance. It prevents gastric ulcers and their associated GI bleeding in patients receiving NSAIDs. Another product, Arthrotec®, combines misoprostol with the NSAID diclofenac sodium in a single pill.

Genitourinary: fluid retention, reduction in creatinine clearance, and acute tubular necrosis with renal failure

Hepatic: acute reversible hepatotoxicity

Cardiovascular: hypertension and moderate to severe noncardiogenic pulmonary edema. All NSAIDs now carry a warning that they may increase the risk of myocardial infarction.

Hematologic: altered hemostasis through effects on platelet function

Other: skin eruption, sensitivity reactions, tinnitus, and hearing loss

Pregnancy and Lactation

NSAIDs should be avoided after the first trimester. NSAIDs appear in breast milk and should be used cautiously by breast-feeding mothers.



Antimalarials

This group of drugs was first developed during World War II because quinine, the standard treatment for malaria, was in short supply. Investigators discovered antimalarials could also be used to treat the joint pain that occurs with rheumatoid arthritis. Subsequent use of antimalarials showed that they are effective in controlling lupus arthritis, skin rashes, mouth ulcers, fatigue, and fever. They have also been shown to be effective in the treatment of discoid lupus erythematosus. Antimalarials are not used to manage more serious, systemic forms of SLE that affect the organs. It may be weeks or months before the patient notices that these drugs are controlling disease symptoms.

Considerations for Health Professionals

Assessment:

History: allergy to salicylates or other NSAIDs, cardiovascular dysfunction, hypertension, peptic ulcer, GI bleeding or other bleeding disorders, impaired hepatic or renal function, pregnancy, and lactation

Laboratory data: hepatic and renal studies, complete blood count (CBC), clotting times, urinalysis, serum electrolytes, and stool for occult blood

Physical: all body systems to determine baseline data and alterations in function, skin color, lesions, edema, hearing, orientation, reflexes, temperature, pulse, respirations, and blood pressure

Evaluation:

therapeutic response, including decreased inflammation and adverse effects

Administration:

with food or milk (to decrease gastric irritation)

Teaching points:

See Patient Information Sheet in Chapter 7 on *Nonsteroidal Anti-Inflammatory Drugs (NSAIDs)*.

Types of Antimalarials

The drugs most often prescribed are hydroxychloroquine sulfate (Plaquenil®) and chloroquine (Aralen®).

Mechanism of Action and Use

The anti-inflammatory action of these drugs is not well understood. In some patients who take antimalarials, the total daily dose of corticosteroids can be reduced. Antimalarials also affect platelets to reduce the risk of blood clots and lower plasma lipid levels.

Side/Adverse Effects

Central Nervous System: headache, nervousness, irritability, dizziness, muscle weakness, and tinnitus

Gastrointestinal: nausea, vomiting, diarrhea, abdominal cramps, and loss of appetite

Ophthalmologic: Visual disturbances and retinal changes are manifested by blurring of vision and difficulty in focusing. A very serious potential side effect of antimalarial drugs is damage to the retina. Because of the relatively low doses used to treat SLE, the risk of retinal damage is quite small: about 1 in 5,000. However, patients should have a thorough eye examination before starting this treatment and yearly thereafter.

Dermatologic: dryness, pruritus, alopecia, skin and mucosal pigmentation, skin eruptions, and exfoliative dermatitis

Hematologic: blood dyscrasia and hemolysis in patients with glucose 6-phosphate dehydrogenase (G6PD) deficiency

Pregnancy

Antimalarials are usually continued during pregnancy. They do cross the placenta, but a clinical trial and case series have not found safety issues.

Considerations for Health Professionals

Assessment:

History: known allergies to the prescribed drugs, psoriasis, retinal disease, hepatic disease, alcoholism, pregnancy, and lactation

Laboratory data: CBC, liver function tests, and G6PD deficiency

Physical: all body systems to determine baseline data and alterations in function, skin color and lesions, mucous membranes, hair, reflexes, muscle strength, auditory and ophthalmologic screening, liver palpation, and abdominal examination

Evaluation:

therapeutic response and side effects

Administration:

before or after meals at the same time each day to maintain drug levels

Teaching Points:

See Patient Information Sheet in Chapter 7 on *Antimalarials*.



Corticosteroids

Corticosteroids are hormones secreted by the cortex of the adrenal gland. SLE patients with symptoms that do not improve or who are not expected to respond to NSAIDs or antimalarials may be given a corticosteroid. Although corticosteroids have potentially serious side effects, they are highly effective in reducing inflammation, relieving muscle and joint pain and fatigue, and suppressing the immune system. They are also useful in controlling major organ involvement associated with SLE. These drugs are given in much higher doses than the body produces and act as potent therapeutic agents. The decision to use corticosteroids is highly individualized and is dependent upon the patient's condition.

Once the symptoms of lupus have responded to treatment, the dose is usually tapered until the lowest possible dose that controls disease activity is achieved. Patients must be monitored carefully during this time for flares or recurrence of joint and muscle pain, fever, and fatigue that can result when the dosage is lowered. Some patients may require corticosteroids only during active stages of the disease; those with severe disease or more serious organ involvement may need long-term treatment.

Treatment with corticosteroids must not be stopped suddenly if they have been taken for more than 4 weeks. Administration of corticosteroids causes the body's own production of adrenal

hormones to slow down or stop, and adrenal insufficiency will result if the drug is stopped suddenly. Tapering the dose allows the body's adrenal glands to recover and resume production of the natural hormones. The longer a patient has been on corticosteroids, the more difficult it is to lower the dose or discontinue use of the drug.

Types of Corticosteroids

Prednisone (Orasone[®], Meticorten[®], Deltasone[®], Cortan[®], Sterapred[®]), a synthetic corticosteroid, is most often used to treat lupus. Others include hydrocortisone (Cortef[®], Hydrocortone[®]), methylprednisolone (Medrol[®]), and dexamethasone (Decadron[®]). Corticosteroids are available as a topical cream or ointment for skin rashes, as tablets, and in injectable form for intramuscular or intravenous administration.

Mechanism of Action and Use

The frequently prescribed corticosteroids are highly effective in reducing inflammation and suppressing the immune response. These drugs may be used to control exacerbation of symptoms and are used to control severe forms of the disease. These drugs are usually administered orally. During periods of serious illness or prior to surgery, they may be administered intravenously; once the patient has been stabilized (or patient is able to have oral fluids after surgery), oral administration should be resumed.

Side/Adverse Effects

Central Nervous System: depression, mood swings, and psychosis

Cardiovascular: congestive heart failure (CHF) and hypertension*

Endocrine: Cushing's syndrome, menstrual irregularities, and hyperglycemia

Gastrointestinal: GI irritation, peptic ulcer, and weight gain

Dermatologic: thin skin, petechiae, ecchymoses, facial erythema, poor wound healing, hirsutism,* urticaria, and acne

Musculoskeletal: muscle weakness, loss of muscle mass, and osteoporosis*

Ophthalmologic: increased intraocular pressure, glaucoma, exophthalmos, and cataracts*

Other: immunosuppression and increased susceptibility to infection

Pregnancy and Lactation

Corticosteroids cross the placenta, but can be used cautiously during pregnancy. They also appear in breast milk; patients taking large doses should not breastfeed.

Considerations for Health Professionals

Assessment:

History: hypersensitivity to corticosteroids, tuberculosis, infection, diabetes, glaucoma, seizure disorders, peptic ulcer, CHF, hypertension, and liver or kidney disease

Laboratory data: electrolytes, serum glucose, white blood cell (WBC) count, cortisol level

Physical: all body systems to determine baseline data and alterations in function, weekly weight gain of >5 pounds, GI upset, decreased urinary output, increased edema, infection, temperature, pulse irregularities, increased blood pressure, and mental status changes (e.g., aggression or depression)

Evaluation:

therapeutic response, including decreased inflammation and adverse effects

Administration:

with food or milk (to decrease GI symptoms)

Teaching Points:

See Patient Information Sheet in Chapter 7 on *Corticosteroids*.

* long-term effects

Immuno-suppressives

Immunosuppressive agents are generally used to reduce rejection of transplanted organs. They are also used in serious, systemic cases of lupus in which major organs such as the kidneys are affected or in which there is severe muscle inflammation or intractable arthritis. Because of their steroid-sparing effect, immunosuppressives may also be used to reduce or sometimes eliminate the need for corticosteroids, thereby sparing the patient from undesirable side effects of corticosteroid therapy.

Immunosuppressives can have serious side effects. Patients need to understand, however, that side effects are dose-dependent and are generally reversible by reducing the dose or stopping the medication.

Types of Immunosuppressives

A variety of immunosuppressive drugs is available to treat lupus. Although they have different mechanisms of action, each type functions to decrease or prevent an immune response. The immunosuppressives most frequently used with SLE patients are:

- **azathioprine (Imuran®).** Azathioprine, one of the most widely used immunosuppressives for lupus, is an antimetabolite. Antimetabolites work by blocking metabolic steps within immune cells and then interfering with immune function. Used to control the underlying disease process, azathioprine has fewer serious side-effect risks than some other drugs used to control lupus.
- **cyclophosphamide (Cytoxan®).** An alkylating agent and strong immunosuppressive, cyclophosphamide is reserved for treating lupus with kidney disease or other internal organ involvement. It works by targeting and damaging autoantibody-producing cells, thereby suppressing the hyperactive immune response and reducing disease activity. It has the potential for severe side effects, including risk of serious infection.
- **methotrexate (Rheumatrex®).** Originally developed as a cancer treatment and later approved for rheumatoid arthritis, methotrexate, like azathioprine, is an antimetabolite. It is predominantly used for lupus arthritis. It requires monitoring of the CBC and liver function tests. To reduce toxicity, daily folic acid is prescribed.
- **cyclosporine (Neoral®).** Originally developed to prevent the body from rejecting transplanted organs, cyclosporine is now commonly used to treat rheumatic diseases, including lupus. Cyclosporine is an antimetabolite.
- **mycophenolate mofetil (CellCept®).** A strong immunosuppressive drug developed to prevent the rejection of transplanted organs, mycophenolate is sometimes used as an alternative to cyclophosphamide for

lupus with kidney involvement. Mycophenolate works by keeping T and B lymphocytes from replicating.

There are many serious risks associated with the use of immunosuppressives. They include immunosuppression (resulting in increased susceptibility to infection), bone marrow suppression (resulting in decreased numbers of RBCs, WBCs, and platelets), and development of malignancies.

Side/Adverse Effects

Dermatologic: alopecia (cyclophosphamide and methotrexate)

Gastrointestinal: nausea, vomiting, stomatitis, esophagitis, and hepatotoxicity

Genitourinary: hemorrhagic cystitis, hematuria, amenorrhea,* impotence,* and gonadal suppression (cyclophosphamide only) **

Hematologic: thrombocytopenia, leukopenia, pancytopenia, anemia, and myelosuppression

Respiratory: pulmonary fibrosis***

Other: increased risk of serious infections or malignancies

Pregnancy and Lactation

Use of immunosuppressives presents definite risks to the fetus. Female patients should use contraceptive measures during treatment and for 12 weeks after ending

* temporary or reversible once drug therapy is discontinued

** recovery of function after drug is discontinued is unpredictable

*** with high doses

Considerations for Health Professionals

Assessment:

History: allergy to immunosuppressive drugs, infections, impaired hepatic or renal function, pregnancy, lactation, corticosteroid therapy, immunosuppression, bone marrow suppression, and appropriate contraception

Laboratory data: CBC, differential, platelet count, renal function studies, liver function tests, pulmonary function tests, chest X ray, and electrocardiogram (ECG)

Physical: all body systems to determine baseline data and alterations in function, temperature, pulse, respiration, weight, skin color, lesions, hair, and mucous membranes

Evaluation:

therapeutic response and adverse effects

Administration:

orally or intravenously

Precaution: Drug administration protocols can vary. The nurse must work closely with the prescribing physician to administer the drug safely and to monitor the patient to minimize adverse effects and achieve expected outcomes.

Teaching Points:

See Patient Information Sheets in Chapter 7 on *Azathioprine*, *Cyclophosphamide*, *Methotrexate (Rheumatrex®)*, *Cyclosporine (Neoral®)*, and *Mycophenolate Mofetil*.

azathioprine therapy. Azathioprine may pass into breast milk, and women using this drug should consult with their doctors before breastfeeding.

IVIgs may be used to control SLE with



Intravenous Immunoglobulins (IVIgs)

organ involvement or vasculitis. Although the mechanism by which these products help is not well-understood, it is thought that they reduce antibody production or promote the clearance of immune complexes from the body.

Risks

Although an IVIg, like any drug, can cause potentially dangerous side effects, it doesn't suppress the immune system the way immunosuppressives and corticosteroids do. Thus, the risk of serious infections with these drugs is less.

Side/Adverse Effects

Dermatologic: rash, mild skin reaction at injection site

Gastrointestinal: abdominal cramps, nausea, vomiting

Musculoskeletal: chest, back or hip pain; muscle pain; joint pain

Neurologic: anxiety, chills, dizziness, fever, headache

Other: chest tightness, difficulty breathing, burning sensation in the head

Considerations for Health Professionals

Assessment:

History: allergy to Igs; sepsis; volume depletion; IgA deficiency; paraproteinemia; renal insufficiency; diabetes mellitus; methotrexate; and virus vaccines

Laboratory data: CBC; white blood cell differential count; renal function studies, including measurement of blood urea nitrogen (BUN)/serum creatinine; liver function tests; pulmonary function tests; chest X ray; and electrocardiogram (ECG)

Physical: all body systems, to determine baseline data and alterations in function; temperature; pulse; respiration; weight; skin color; lesions; hair; and mucous membrane

Evaluation:

therapeutic responses and adverse effects

Administration:

Intravenously. The dose is 400 mg/kg for 5 days. The nurse must work closely with the prescribing physician to administer the drug safely and to monitor the patient to minimize adverse effects and achieve expected outcomes. Some patients experience headaches that can be helped by slowing the infusion.

Teaching Points:

See Patient Information Sheet in Chapter 7 on *Intravenous Immunoglobulins (IVIgs)*.



Other Drugs

In addition to these commonly used classes of medications, there are a number of other medications used, often experimentally, to treat lupus. These include thalidomide and dehydroepiandrosterone (DHEA).

- **Thalidomide** is a notorious sleep aid that was pulled from the market in European countries when people discovered it caused birth defects. However, it is showing effectiveness as a treatment for skin manifestations of lupus.

Although its precise mechanism is not clear, thalidomide inhibits inflammatory cytokines in the skin and underlying blood vessels.

Thalidomide carries the risk of many side effects, including abdominal pain, infection, chills, diarrhea, liver abnormalities, anemia, peripheral edema, hyperlipidemia, leukopenia, insomnia, sensory neuropathy, albuminuria, hematuria, ovarian failure, and thrombosis.

Because of the risk of birth defects, it is strictly contraindicated in women who are pregnant or might become pregnant. Scientists are working on developing a safer version of thalidomide. A number of other drugs are used to treat specific manifestations of lupus.

- **DHEA** is a weak male hormone used by the body to make other hormones, including testosterone and estrogen. It appears to benefit women with lupus by helping to restore the balance of male-female hormones.

The manufacturer of the DHEA product Prestara® recently completed a phase III clinical trial to determine if DHEA improves bone mineral density in women with lupus who are receiving corticosteroid therapy. There was a modest change at 1 year. An earlier study of the drug confirmed Prestara®'s ability to improve or stabilize clinical outcome and disease symptoms in women with mild-to-moderate lupus.

The FDA did not approve DHEA for treating lupus. In the meantime, patients may get DHEA from a compounding pharmacist. If you have patients using DHEA, it is important to stress that they purchase a medical-grade product from a pharmacy and have regular check-ups to monitor response to the drug.

DHEA is never used in men with lupus. In postmenopausal women, mammograms and PAP smears must be monitored.

Chapter 6

Psychosocial Aspects
of Lupus



Lupus is a chronic disease that defies easy description. A diagnosis may not be made for a long time. Diagnostic difficulties coupled with the serious, chronic nature of the disease present the patient, family, and the medical team with many challenges. For people with lupus, psychosocial issues can be a major part of living with this illness.

Health professionals need to be aware of these issues to achieve excellent, comprehensive care of people with lupus. Because lupus is a chronic disease of flares and remissions, each exacerbation of the disease can raise new issues of coping for the patient. This chapter describes concerns typically raised by people with lupus and their families. Each of these concerns is an opportunity for the nurse or other health professional to provide education and to help people explore feelings and resolve problems.



Seeking a Diagnosis

It may take some time for a patient to be definitively diagnosed with lupus. During this time, patients may be confused or frustrated by the seeming inability of the doctors they visit to confirm the diagnosis. They may ask, “Why don’t the doctors know?” Part of the difficulty, both for the patient and the doctor, rests in the fact that the diagnosis may seem to be hiding in a forest of confusing, vague, or changeable symptoms. A patient may express some of the following sentiments or frustrations:

“My symptoms are bizarre – they’re here today and gone tomorrow.”

“I can’t put a handle on my symptoms. I’ll have one today and a totally new one tomorrow.”

“No one seems to believe me. My family thinks it is all in my head and they want me to see a psychiatrist. I am beginning to wonder if it is all in my head.”

Before a diagnosis is made, many of a patient’s primary needs are emotional. A lupus patient will, in all likelihood, be on intimate terms with her or his symptoms long before their cause is known. Realistically, she or he is the best authority on these symptoms. A patient may feel frustrated if, after describing symptoms, others do not respect her or his knowledge or do not share the conviction that something is wrong. If the doctor, family, or friends are unsupportive, the patient’s fear, anger, and sense of isolation will only

increase. These feelings add stress, which in turn can exacerbate the disease.

Health professionals can help ease these feelings by showing empathy during this difficult time and by reassuring the patient that the symptoms are real and merit serious attention. In addition, treating the patient as a whole person, and not just as a subject with a disease, can be immensely valuable in establishing a trusting relationship with the patient. Such a relationship will help the patient speak freely about symptoms or concerns that she or he may have been unwilling to discuss previously.



After the Diagnosis

Patients will certainly experience a sense of relief once their condition is finally given a name and a tangible identity. At the same time, other emotions – anger, fear, depression, confusion, grief – may also surface. Patients may express some of the following sentiments:

“At last – a diagnosis! Now I know why I feel the way I do.”

“Why me?”

“I’ll never be able to make plans, because I don’t know what tomorrow will bring.”

“I feel guilty for having lupus and for all the trouble it’s causing my family.”

“Should I tell everyone or keep it quiet?”

“Will I lose my job?”

“I hate this disease. It’s destroying my life and my family.”

“I’m scared.”

“Will I die soon?”

“Will I ever be able to have children?”

“How will we pay all these medical bills?”

After the diagnosis, some patients will have an insatiable desire for information about the disease; others may need to work through intense emotions before they can come to grips with their illness and begin to cope productively. The rapport that the health professional has established with the patient can now be used to provide the patient with information, resources, and an accepting atmosphere in which to adjust emotionally. This rapport can set a foundation of hope.

Living with Lupus: Key Issues

Every day, the patient living with lupus confronts a range of issues, from the emotional reactions of a spouse, children, or work colleagues to her or his own fluctuating physical and psychological state. The thoughtful and sympathetic health professional can contribute greatly by helping the patient see these issues objectively, understand that they will come and go over time, and develop effective coping skills.

Family Issues

One of the most important emotional issues that people with lupus grapple with is the ongoing and changeable reactions of those closest to them: parents, a spouse, or children. Understanding family dynamics can help the health professional work with the patient to develop positive coping strategies.

Parents

Parents of a lupus patient may react by smothering or – the other extreme – by not taking the disease seriously. Because lupus may be genetic, some parents may feel guilty for having “given” their child the disease. The patient may hear sentiments such as:

“Oh, my poor baby, let me take care of everything.”

“Don’t make such a big deal of it. Just shake it off.”

“If it’s genetic, I must have given it to you.”

Spouse or Partner

A spouse or partner often experiences many of the same strong emotions the lupus patient does. Grief, fear, and anger are common emotions for spouses or partners as they deal with the patient’s changing physical condition. Well-established roles and responsibilities within the family may change, leading to confusion or conflict. These changes and feelings can affect the daily workings of the relationship, even threatening its foundation:

“I want you to get well. I want you to be the same as when I met you.”

“I’m afraid you will die and leave me and the children.”

“I’m confused. Our roles keep changing, and then changing back.”

“It’s hard doing my job and yours, too. I’ll never learn how to do the work around the house well enough to suit you.”

“I’m angry that you feel sick all the time and can’t do what you used to. I feel guilty for being angry.”

“Lupus has damaged our sex life. You’re always too tired, and I’m afraid I’ll hurt you.”

“I need to mourn our losses, too.”

Children

It is difficult for the children of a lupus patient to deal with the large and complex issues raised by having a sick parent. Some of these issues are tangible, whereas others are scary precisely because of their abstract, unknown nature. Because younger children have difficulty articulating their feelings and concerns, these emotions may go unnoticed or may be acted out in negative or disruptive behaviors. Older children with younger siblings may feel resentment as well as concern. Children’s fears and feelings may emerge in statements such as:

“We never play anymore because you’re always tired or sick.”

“Is something terrible going to happen to you? Will you go away forever?”

“You’ve denied me my childhood. I don’t want to be responsible for my little brother all the time.”

The Patient’s Own Physical and Emotional State

The physical repercussions of lupus, such as fatigue, weight gain, or an increased sensitivity to sunlight, can trigger intense emotional reactions. The following sentiments illustrate some common physical and emotional experiences of people with lupus:

Fatigue

“Nobody understands how it feels to be this tired.”

“I feel like I’m trying to move through molasses. Even my bone marrow feels tired.”

“No matter what I do or how much sleep I get, I still wake up tired.”

“Between pain, stiffness, and fatigue, I feel like an old, old person.”

Personal Appearance

“Why do I look so awful? I don’t even look like myself.”

“I don’t want anyone to see the rash on my face.”

“I used to have beautiful thick hair.”

“I hate the fact that I eat so much, but this medicine makes me hungry all the time. I keep gaining weight.”

Physical and Mental Abilities

“I’ve always loved sitting out in the sun. Now I can’t anymore.”

“I can’t do the outdoor recreational things I used to do. I feel I’m letting my family down by not being able to play outdoors with them.”

“Does anyone else have memory lapses? I’m afraid something terrible may happen because I’ll forget something really important.”

Depression

“I’m always on the verge of tears.”

“I don’t want to leave the house.”

“I can never make plans, because I don’t know what tomorrow will bring.”

“Sometimes I think my family and friends would be better off without me.”

The Future

“I’ve taken too much sick leave at work.”

“Should I tell my boss I have lupus? I’m afraid I’ll lose my job, and we really need the money.”

“Will I pass the disease on to my children?”

“What will happen as I grow older? Am I going to die from this disease?”



Living with Lupus: Developing Effective Coping Skills

Many people with lupus go through phases in which they feel that control over their life is slipping from their own hands into those of an unpredictable and unpleasant disease. This sense of powerlessness can occur not only during flares but also during periods of recuperation and remission. It forces the patient to choose between two options. This choice may be made many times during the course of the illness.

The first option is for the patient to submit to the disease and accept lupus and a lifestyle of illness as her or his identity. This choice may appear attractive to a newly diagnosed patient who is exhausted from the long battle of uncertainties related to lupus or to a long-term patient who is exhausted from fighting the disease. However, this option offers a life of self-pity, negativity, and significantly diminished horizons.

The second option is for patients to create a new identity based on reworked, realistic goals and expectations. Inherent in this second option is a sense of greater control, an improved self-image, and a positive and hopeful attitude. This option requires imagination, resilience, and determination, and depends heavily on the existence of an adequate support network that can reinforce gains and buffer the occasional disappointment. This option offers true quality of life.

Perhaps the greatest gift that the health professional can offer patients is the opportunity to choose this second option. This gift can be given in several ways.

Help Patients Gain Control Over Feelings and Emotions

Patients must first assess their needs and the needs of those around them; evaluate their personal strengths, resources, and weaknesses; and develop effective communication strategies for dealing with family, friends, and the health care team. The health professional can assist the patient or suggest other professionals who can help. Many health professionals – for example, nurses, health educators, psychologists and psychiatrists, social workers, and occupational and physical therapists – are experienced in rheumatology and lupus. These professionals can educate family and friends about the needs and circumstances of people with lupus. The health professional can also encourage the patient to seek out other supportive mechanisms, such as:

- local support groups
- educational and self-management programs offered by the Lupus Foundation of America, the Arthritis Foundation, and the SLE Foundation
- pen pals.

Help Patients Gain Control Over Their New Physical Limitations

People with lupus 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. Health professionals can help patients develop an effective self-management program that sets out achievable goals, realistically paces activities, and avoids over commitments.

Help Patients Gain Control Medically

Doctors, nurses, and other professionals involved in lupus care can teach patients about many medical aspects of the disease, such as warning signs of an impending flare (the patient may have much to contribute to this discussion), medication use, possible side effects, and warning signals for contacting medical personnel. Nurses can also teach strategies for communicating with the health care team. This knowledge and these strategies will help the patient gain a sense of increased medical control over the disease. The Patient Information Sheets in Chapter 7 can help with this process.



Living with Lupus: A Brighter Tomorrow

Research advances are increasing the understanding of lupus and leading to improved treatments and medications. These advances and a growing body of practical experience in living with and controlling lupus point to a prognosis for people with lupus that is far brighter than it was even 25 years ago. Nurses and other health professionals who work on a continual basis with people who have lupus can have significant roles in improving the emotional and psychological status of patients so that they can take advantage of this brighter tomorrow.

Chapter 7

Patient Information



Caring for the lupus patient involves a number of critically important elements. Providing medical care as directed by the patient's doctor; monitoring the patient's physical status over time; and being sympathetic, understanding, and supportive are all involved. Educating patients and encouraging them to learn about their disease is another crucial element.

The Patient Information Sheets in this chapter cover a range of topics about lupus and lupus medications and can help with this aspect of patient care. The titles are:

	Sheet
■ Living With Lupus	1
■ Preventing Fatigue Due to Lupus	2
■ Exercise and Lupus	3
■ Preventing a Lupus Flare	4
■ Serious Conditions Associated With Lupus	5
■ Joint Function and Lupus	6
■ Skin Care and Lupus	7
■ Fever and Lupus	8
■ Nutrition and Lupus	9
■ Sexuality and Lupus	10
■ Pregnancy and Lupus	11
■ Nonsteroidal Anti-Inflammatory Drugs (NSAIDs)	12
■ Antimalarials	13
■ Corticosteroids	14
■ Azathioprine	15
■ Cyclophosphamide	16
■ Methotrexate	17
■ Cyclosporine	18
■ Mycophenolate Mofetil (CellCept®)	19
■ Intravenous Immuno-globulins (IVIGs)	20

Teaching the Lupus Patient

The Patient Information Sheets provide a wealth of information, and are written in language that most patients will find easy to understand. Health professionals should hand them out to patients as appropriate during their discussions on specific issues related to lupus. The sheets can be printed directly from this guide, or they can be downloaded from the Web site of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS): www.niams.nih.gov. The following points may help health professionals use them effectively.

Use the Sheets to Complement Existing Teaching Efforts

Over time, the doctor and other members of the health care team will probably discuss with a patient much of the information contained in these sheets. However, some patients may not absorb all the information given to them verbally. The Patient Information Sheets can be a useful backup. As the health professional talks through an issue, he or she may want to refer to or highlight specific sections of a sheet. This will help to reinforce the information and show the patient where to find it later.

Use the Sheets Selectively

The Patient Information Sheets cover a wide range of issues. Not all of them will be appropriate for each patient. For example, the sheet on *Serious Conditions Associated With Lupus*

would not be appropriate for a patient with mild lupus. On the other hand, the sheets on *Skin Care and Lupus* and on *Preventing Fatigue Due to Lupus* may be particularly useful for that patient. One approach is to give the patient several of the more general Patient Information Sheets initially, then see which others are relevant as time goes on. When patients are first given a prescription for a lupus medication, they should also receive the Patient Information Sheet on that medication.

Use the Sheets in Tandem

The information contained in a number of the Patient Information Sheets is complementary, and it may be helpful to give the patient several sheets together. For example, the sheets on *Exercise and Lupus* and *Joint Function and Lupus* would work well together, as would the sheets on *Fever and Lupus* and *Nonsteroidal Anti-Inflammatory Drugs or Corticosteroids*. Several of the sheets that contain more general information, such as *Living With Lupus* or *Preventing a Lupus Flare*, would be a good complement to many of the sheets dealing with more specific topics.

Living with Lupus

You have recently been diagnosed with a disease known as systemic lupus erythematosus (SLE). It has probably taken time to arrive at this diagnosis. Now that you know, you may feel relieved but also overwhelmed. You probably have a lot of questions about lupus.

You may have a mild or a more serious form, but no matter how severe your lupus is, you will need close medical supervision. You may also need to make lifestyle changes to keep your disease under control and feel as well as possible. At the beginning, you may feel some of these emotions:

- anger or depression over the change in your health
- uncertainty about what to tell family, friends, or coworkers
- guilt for having lupus and for the burden it may cause your family
- fear that you may lose your job if you can no longer work regularly
- fear that you may die.

These are all normal feelings, and you are not alone in having them. You should give yourself time to adjust to your illness. This may or may not be easy for you. Discuss your feelings and concerns with your doctor and nurse and with your family and friends. Sometimes, talking with other people who have lupus is helpful. If you are having a hard time adjusting to your diagnosis, consider seeking the help of a counselor.

Caring for Yourself

- Learn as much about lupus as possible.
- Understand that you will experience a variety of emotions, particularly when you are first diagnosed and as you adjust to the fact that you have lupus.
- Adopt a positive attitude.
- Evaluate your personal strengths and resources, such as family, friends, coworkers, and community ties.
- Determine what your needs are, then make a plan to address them.
- Don't be afraid to set goals for yourself, but be flexible.
- Learn how to manage the physical aspects of your disease and the effects they have on other areas of your life.
- Learn to deal with stressful situations, because stress and anxiety can make your lupus symptoms worse.
- Learn to talk with your health care team, family, friends, and coworkers about lupus and the effect it has on your life.
- Don't be afraid to seek help for yourself or your family.
- Remember that living well with lupus is possible. It is important that you take control of your illness and not allow it to take control of you. Adopting a positive attitude and striving to be happy can make a big difference in the quality of your life and that of your family and friends.

Many physical and emotional issues confront people with lupus, both in the beginning and throughout the course of their disease. The most common issues include the following.

Fatigue: Fatigue is a chronic problem that is usually accompanied by joint pain and stiffness. It can affect many aspects of your daily life.

Changes in personal appearance: You may experience changes in your personal appearance. Discoid lupus (a form of lupus) may cause sores, blotches, or scarring on the face, arms, shoulders, neck, or back. The medications for lupus can also sometimes change your appearance. For example, corticosteroids can cause weight gain, excessive hair growth, or swelling. Some drugs may cause hair loss. These changes in the way you look can be emotionally challenging to deal with.

Changes in physical ability: Many people with lupus feel isolated because their fatigue and need to rest keep them from maintaining normal work and social schedules. You may feel frustrated if you can't participate in outdoor activities with family or friends because of sensitivity to the sun. There will be times when you may feel it is easier to stay home than to make plans and later cancel them because you are too tired or not feeling well.

Psychological effects of corticosteroids: Corticosteroids are used to treat many of the symptoms of lupus that result from inflammation. Their use can cause anxiety, mood changes, forgetfulness, depression, personality changes, and

other psychological problems. You need to know about the possible side effects of these drugs while you are taking them. It is also important that your family and friends understand the effects of these drugs so that they can be supportive if you should experience any side effects.

Depression: You may feel sad or depressed at times in your struggle to control lupus or because of the medications you take. Good communication with your doctor and health care team, as well as with your family and friends, is important in helping you cope with these feelings.

Concern for the future: Because the future and course of your disease are unknown, planning for your job, your family, and life in general can be difficult at times.

Family concerns: Like you, your family can be overwhelmed about your diagnosis and may have a difficult time understanding and adapting to your disease. They may feel confused, helpless, and afraid. Because of your physical limitations, traditional roles and responsibilities within the family may need to change. It is important that everyone talk openly and honestly with each other. It is also important that your family members learn about your disease so they can better understand your physical and emotional condition and the changes in your family that may result.

Preventing Fatigue Due to Lupus

Fatigue is a very common complaint of all people with systemic lupus erythematosus (SLE), even when no other symptoms of active disease are present. The fatigue of lupus isn't just being tired. You may feel an extreme fatigue that interferes with many aspects of your daily life. You may find that you are unable to participate in your normal pattern of daily activities, such as working, caring for your family and home, or participating in social activities. The exact cause of this fatigue is not known. But in some patients, it is related to fibromyalgia, which is a common, chronic disorder characterized by widespread fatigue and muscle pain, as well as multiple tender points.

Your doctor and nurse will probably ask you about your lifestyle and patterns of daily living and activity. They will also evaluate your overall fitness, health, nutrition, and ability to handle stress. Your doctor or nurse will then be able to advise you about how your fatigue can be reduced. It is important to remember that getting enough rest, maintaining physical fitness, and keeping stress under control are absolutely necessary for anyone with lupus.

Changes in your lifestyle and patterns of daily living and activity may not be easy to accept. In addition, the changes necessary for you to cope with your disease today may be different from the changes you may have to make later. A positive attitude and a well-thought-out, but flexible, plan of action will increase the chances that you can make these changes successfully.

Caring for Yourself

- Get enough sleep. You may be able to get by on 8 hours a night, or you may need more.
- Plan for additional rest periods throughout the day, as needed. Do not exhaust yourself.
- Getting enough rest does not mean no activity at all. A well-designed exercise program is important to maintaining strength, endurance, and overall fitness.
- Every week, make a simple plan of your work and activities. The plan can help you organize the events of your life and ensure that you have a good balance of rest and activity.
- Each day, review your plan and decide if you are physically up to the activities for that day. Be flexible; if you don't have the strength to do an activity today, do it another time.
- Don't try to complete a large task or project all at one time; divide it into several steps.
- Eat a well-balanced diet.
- Dealing with stressful issues and problems takes a lot of energy. If you feel stressed out, talk with your doctor or nurse. They may be able to provide you with help for your problem or direct you to someone else who can.

Additional Notes

Exercise and Lupus

Because lupus causes joint pain and inflammation, muscle pain, and fatigue, the very thought of exercising can be a challenge. In addition, because lupus is a disease that requires a large amount of rest, you might wonder why exercise is so important. Although rest is important in managing fatigue, too much rest can be harmful to muscles, bones, joints, and overall fitness. Keeping fit through an exercise program planned just for you can help you feel better, both mentally and physically. Many types of exercises are appropriate for people with lupus, such as swimming and walking. Regular exercise will:

- increase your muscle strength
- help prevent your joints from getting stiff
- help prevent osteoporosis
- help keep your weight under control
- improve your cardiovascular health
- help reduce stress.

Getting Started Can Be The Hardest Part

- Check with your doctor before you start any type of exercise program. He or she can evaluate your overall condition and fitness and recommend a type and level of activity that are right for you.
- Try to find someone to exercise with; it can be a lot more fun.
- Start slowly. Chart your progress so you can see and take pride in your accomplishment.
- Change your exercise activities depending on how you feel. If you're not up to it on one day, that's okay. Try to go back to your program the next day.

For a healthy person, achieving physical fitness can be a lot of hard work. For a person with lupus, such an achievement is really something to be proud of!

Additional Notes

Preventing a Lupus Flare

Your doctor has put together a treatment plan that is designed specifically for you and your lupus. This probably includes physical and emotional rest, aggressive treatment of infections, good nutrition, and avoidance of direct sunlight and other sources of ultraviolet light. Your doctor may have also prescribed medications to control disease symptoms and other health problems that you might have. One of the most important ways you can help yourself is to understand your treatment plan and the things you need to do to keep your disease under control.

Sometimes, despite the treatment plan and your efforts, you may experience a lupus flare. A flare is a worsening of symptoms that signals increased disease activity. A variety of factors can cause a flare, and you should contact your doctor immediately if you suspect a flare is developing. The doctor will evaluate your condition and take steps to control the seriousness of the flare. He or she will also reevaluate your overall treatment plan and make any needed changes.

Warning Signs of a Flare

- increased fatigue
- a new or higher fever
- increased pain
- development or worsening of a rash
- development of symptoms you haven't had before
- swollen joints

What Triggers a Flare?

A flare can be triggered by one factor or a combination of factors. The most common are:

- overwork or not enough rest
- stress or an emotional crisis
- exposure to sunlight or other sources of ultraviolet light
- infection
- injuries or surgery
- pregnancy or the time right after the baby's birth (the postpartum period)
- sudden stopping of medications for lupus
- certain prescription drugs, such as sulfonamide antibiotics
- over-the-counter medications, such as echinacea.

Caring for Yourself

- Learn to recognize the warning signals of a flare and tell your doctor about them.
- Maintain your physical health. Be sure to visit your doctor regularly, even if you are feeling well. Schedule regular dental, eye, and gynecological exams.
- Get enough sleep and rest. Be flexible with your schedule of daily activities.
- Try to limit your stress. Because this may be hard to do at times, consider developing a plan for dealing with potentially stressful situations. Develop a support system that includes family, friends, medical or nursing professionals, community organizations, and support groups. Remember, it helps to talk to someone when you're feeling stressed.
- Participate in a well-planned exercise program to help maintain physical fitness and reduce stress.
- Eat a healthy diet.
- Limit your exposure to the sun and other sources of ultraviolet light, such as fluorescent or halogen lights.
- Tell your doctor right away about any injury, illness, or infection or if you do not feel well in any way.
- Delay elective surgery (including dental surgery and teeth pulling) until your lupus is under control or in remission.
- Lupus may cause problems for a pregnant woman and her baby. As a result, women with lupus should carefully plan any pregnancy. Do not stop using your method of birth control until you have discussed the possibility of pregnancy with your doctor and he or she has determined that you are healthy enough to become pregnant.
- Talk with your doctor before you stop taking any prescribed medications.
- Check with your doctor or nurse before taking any over-the-counter medications.
- Be careful when trying any over-the-counter preparations used on your skin or scalp. First, determine whether you have a sensitivity or an allergy to it. Put a small amount of the preparation on the inside of your forearm or on the back of your ear. If any redness, rash, raised areas, itching, or pain develops, do not use the preparation.
- Be aware that certain prescription drugs may trigger a flare. Tell any doctor, nurse, or health care professional you visit that you have lupus. Also tell your lupus doctor or nurse if any new medications have been prescribed for you.
- Be sure to check with your lupus doctor before receiving any immunization. Routine immunizations, including those for the flu and pneumonia, are an important part of maintaining your health, and you should get them if your doctor approves.

Serious Conditions Associated With Lupus

Although lupus can be well controlled in many people, serious medical conditions caused by or associated with the disease can still occur. It is important that you know about these conditions and how they may make you feel so that you can call your doctor right away. The sooner a problem is detected and evaluated, the sooner it can be treated to prevent or reduce damage to your body's organs.

Kidney disease: Many people with lupus develop some form of mild kidney disease. Others, however, develop kidney disease serious enough to lead to kidney failure. Warning signs include:

- swelling around your ankles, hands, and eyes
- increased fatigue or tiredness, especially if you have not altered your rest and activity patterns
- increased need to urinate at night.

Pericarditis: This is an inflammation of the thin sac that surrounds the heart. Warning signs include:

- chest pain
- shortness of breath
- new or higher-than-usual fever.

Myocarditis: This is an inflammation of the heart muscle. Warning signs include:

- chest pain
- shortness of breath
- new or higher-than-usual fever.

Atherosclerosis: This is a condition in which fatty deposits build up on the inside of arteries. These deposits can reduce or block blood flow. A blockage or reduced blood flow through an artery that supplies the heart can cause a heart attack to occur. Warning signs include:

- burning, choking, squeezing, or pressing chest pain felt in the center of the chest that may radiate to the left shoulder and arm (anginal pain). This can last up to 5 minutes, and will become much less intense or go away completely if you rest.
- crushing, prolonged chest pain that is not relieved by rest
- shortness of breath
- unrelieved indigestion and a weak or faint feeling.

Pleuritis: This is an inflammation of the lining of the lung. Warning signs include:

- shortness of breath
- chest pain, especially when taking a deep breath.

Central nervous system (CNS) disease: CNS disease covers a variety of problems that may or may not be related to lupus. Problems can include seizures, memory loss, headache, confusion, hearing and visual changes, muscle weakness, depression, and emotional disturbances. Because many of these problems can be related to use of medications or indicate other conditions, it is often difficult to make a definite diagnosis of CNS disease. Warning signs include:

- seizures
- periods of forgetfulness, restlessness, or confusion
- new or increased hearing and vision problems
- bizarre or erratic changes in behavior
- mood swings
- coma
- paralysis
- numbness
- signs of a stroke, including weakness or numbness in the arms, legs, face, or down one side of the body; a change in speech; confusion; or severe headaches.

Depression: With depression, people may feel helpless, hopeless, or overwhelmed. They may find it difficult to get through the day. Depression can occur as a result of lupus or be caused by the drugs used to treat it, especially corticosteroids. Warning signs include:

- depressed mood
- significant weight loss or gain
- trouble sleeping or sleeping too much
- extreme tiredness and lack of energy
- decreased concentration or an inability to make a decision
- feelings of being overwhelmed and unable to carry out simple tasks, such as personal hygiene, housework, or childcare
- feelings of hopelessness about various aspects of life
- unusual anger or irritability
- recurrent thoughts of death and suicide.

Osteonecrosis: This is a condition that usually affects the hip joint, but may occur in other joints such as the knees, ankles, or shoulders. Blood supply to the joint is reduced and, over time, leads to severe degenerative arthritis. Osteonecrosis is considered to be a side effect of corticosteroid therapy and not a manifestation of lupus itself. Warning signs include:

- sharp pain in the groin or buttocks that may radiate down the back of the leg
- decreased exercise tolerance
- stiffness of the hips
- increased pain and difficulty in walking after exercise.

Pancreatitis: This condition causes the pancreas (an organ involved in digestion and in producing hormones that regulate blood sugar levels) to become inflamed. It is a very serious problem that must be treated immediately. Warning signs include:

- sharp, intense pain at the level of the belly button that radiates around to the back
- nausea and vomiting
- new or higher-than-usual fever.

Additional Notes

Joint Function and Lupus

Joint pain or arthritis is experienced by 95 percent of people with lupus at some time during the course of their disease. In fact, joint pain is usually the first symptom of lupus. Unlike rheumatoid arthritis, the arthritis of lupus tends to be temporary. It is also less damaging to the joints. The joints most commonly involved are those of the fingers, wrists, and knees. Elbows, ankles, and shoulders are not affected as often. When a particular joint is affected on one side of the body, the same joint on the other side of the body is usually affected as well.

Arthralgia: This word means “joint pain.” Morning stiffness, swelling, or heat in the joints can also occur.

Myalgia or myositis: Myalgia means “pain in the muscles,” while myositis means “inflammation of the muscle.” These may include overall muscle pain and tenderness, especially in the upper arms and upper legs. Most numb pain in patients with lupus is not due to lupus, but to fibromyalgia, which is a common, chronic disorder characterized by widespread fatigue and muscle pain, as well as multiple tender points.

Other joint complications: Several types of joint complications occur rarely in lupus. They include osteonecrosis (damage to the hip joint that leads to severe arthritis), development of nodules in the small joints of the hands, tendinitis, tendon rupture, and carpal tunnel syndrome. Your doctor or nurse can give you more information about these problems.

Taking Care of Your Joints

If you have joint or muscle problems, the first goal is to keep pain at a tolerable level. You can do this in several ways:

- Apply heat or cold to the affected joints.
- Support the affected joints with pillows, blankets, or splints (if ordered by your doctor).
- Rest the affected joints as much as possible and keep them elevated to reduce swelling.
- Follow your doctor’s plan for managing pain and using anti-inflammation medication.

Your second goal is to maintain joint function and increase muscle strength. You can do this by using the following techniques:

- Take warm showers or baths to lessen stiffness.
- Don’t put any weight on an acutely inflamed joint. Sit or lie down. Avoid strenuous activity and avoid any activity that causes increased pain, swelling, tenderness, or heat to the affected joint.
- Ask a physical therapist or trained family member or friend to gently move the inflamed joint in all the directions it can be moved (this is called passive range of motion [ROM]). This will help prevent stiffness. Your doctor can let you know when and how often this should be done.
- Gently move the affected joint yourself when the acute inflammation is over.

- Talk with your doctor or nurse about physical or occupational therapy if you are having trouble regaining joint strength and motion or if activities of daily living (cooking, cleaning, bathing, etc.) are still difficult.
- Hire a housekeeper or someone to help care for yourself or your children until you feel better.

When you are feeling better and your physical condition has improved, your doctor will probably recommend an exercise program tailored to your needs. Although rest and protecting joint function are extremely important, exercise is also necessary to keep muscles, bones, joints, and tendons strong and healthy. A well-planned exercise program combined with other aspects of your care will help you maintain joint function and improve your overall fitness.

Additional Notes

Skin Care and Lupus

Skin problems are very common in people with lupus. Some skin rashes and sores (also called lesions or ulcers) are very specific to lupus, while others can occur in other diseases as well. Sensitivity or too much exposure to the ultraviolet (UV) rays of sun and to some types of artificial light are responsible for aggravating some rashes and lesions. Many types of skin conditions are common in lupus.

Butterfly rash: This rash over the nose and cheeks can range from a faint blush to a rash that is very severe, with scaling. It is very sensitive to light and appears to get worse when skin is exposed to sun or certain types of artificial light. The rash may be permanent or may come and go.

Discoid lesions: These scarring, coin-shaped lesions are seen on areas of the skin that have been exposed to UV light. They may also occur on the scalp and produce a scarring, localized baldness that is permanent.

Subacute cutaneous lesions: These nonscarring, red, coin-shaped lesions are very sensitive to UV light. They can appear scaly and can mimic the lesions seen in psoriasis. They may occur only on the face or cover large areas of the body.

Mucous membrane lesions: Mouth ulcers are sometimes seen in people with lupus. Nose and vaginal ulcers may also occur. These lesions are usually painless.

Hair loss: In addition to losing hair because of discoid lesions, some people with lupus may develop a temporary, generalized hair loss followed by the growth of new hair. Hair loss may also be caused by infection or by use of corticosteroids or other lupus medications. A severe lupus flare could result in defective hair growth, causing the hair to be fragile and break easily.

Vasculitis: This is a condition in which the blood vessels become inflamed. Very small blood vessels can break and cause bleeding into the tissues, resulting in tiny, reddish-purple spots on the skin known as petechiae (pe-teke-ee-ah). Larger spots are called purpura and may look like a bruise. Vasculitis can also cause blood clots to form, skin ulcers to develop, and small black areas to appear around fingers and toenails. These black areas are a sign of serious tissue damage. If they begin to develop, see your doctor immediately.

Caring for Yourself

- Reduce your exposure to the sun and to some sources of artificial light (especially fluorescent and halogen bulbs). The skin of people with lupus is very sensitive to the UV light that comes from these sources.
- Limit outdoor activity between the hours of 10 a.m. and 4 p.m. This may mean a big change in your lifestyle if you work or play outdoors a lot.
- Wear sunscreen on exposed areas of skin. It should have a sun protection factor (SPF) of 15 or higher. To be sure that your sunscreen protects against both UVA and UVB rays, look for one labeled broad-spectrum protection, or look for ingredients such as micronized zinc oxide or titanium dioxide that block both UVA and UVB.
- Wear sunscreen all year round and on cloudy days as well as on sunny days. Also wear it indoors if you spend a lot of time in a room with many windows (UVA rays can penetrate glass).
- Wear protective clothing, such as hats with wide brims and clothing made of tightly woven material. Thin, loosely woven material allows UV light to penetrate to the skin. If you are very sensitive to the sun, you may want to try specially designed UV- protective clothing.
- Be aware of fluorescent light and halogen lamps. Found in many places, they include floor lamps, overhead lights, photocopiers, and slide projectors. Sunscreen and protective clothing can help. If you work in an office that has fluorescent lights, ask whether you can remove the bulbs directly over your work area, and use a desk lamp if necessary.
- Tell your doctor immediately if any rash or sore appears or gets worse.
- If your doctor prescribes a medication for your skin condition, be sure to take it as directed.
- Try rinsing your mouth with salt water and eating soft foods if you have mouth ulcers. A number of other treatments and preparations are available to treat mouth ulcers as well as those in the nose and vagina.
- Avoid preparations or medications you know will make your skin condition worse. These might include products such as hair dyes and skin creams. Also, some drugs can make you more sensitive to the sun. These include tetracycline antibiotics, diuretics and, ironically, some of the drugs (nonsteroidal anti-inflammatory drugs, methotrexate, hydroxychloroquine) used in lupus treatment. Be particularly conscious of sun protection if you are taking any of these drugs.
- It's okay to wear makeup, but try hypoallergenic brands. A brand that also includes UV protection would be good to use.
- If you have Raynaud's phenomenon, dress warmly in cold weather. Pay particular attention to keeping your hands and feet warm. Keeping your home warm will also help prevent an attack. Avoid smoking, caffeine, and stress – all of these can contribute to Raynaud's phenomenon.
- If you have trouble maintaining a positive attitude about your appearance or your lupus, call your doctor or nurse to discuss your feelings and concerns.

Additional Notes

Fever and Lupus

Fever is often a part of lupus. For some people with lupus, an intermittent (coming and going) or continuous low-grade fever may be normal. Other people, especially those taking large doses of aspirin, nonsteroidal anti-inflammatory drugs (NSAIDs), or corticosteroids, may not have fever at all because these drugs may mask a fever.

If you have lupus, you may be more vulnerable to certain infections than other people who don't have lupus. In addition, you may be more prone to infection if you are taking any immunosuppressive drugs for your lupus. Be alert to a temperature that is new or higher than normal for you, because it could be a sign of a developing infection or a lupus flare.

Caring for Yourself

- Take your temperature at least once a day (or more often if needed) to determine what a "normal" temperature is for you.
- Take your temperature and watch for a fever any time you feel chills or do not feel well.
- Call your doctor immediately if you have a new or higher-than-normal temperature.
- Even if you don't have a fever, don't hesitate to call your doctor if you do not feel well in any way, particularly if you are taking aspirin, NSAIDs, or a corticosteroid. Signs of infection other than a fever include unusual pain, cramping or swelling, a headache with neck stiffness, cold or flu symptoms, trouble breathing, nausea, vomiting, diarrhea, or changes in urine or stool.
- Talk to your doctor about immunization against pneumococcal pneumonia and the flu.
- Practice good personal hygiene.
- Avoid large crowds and people who are sick.

Nutrition and Lupus

Good nutrition is an important part of the overall treatment plan for your lupus. A well-balanced diet provides the necessary fuel for your body to carry on its normal functions. Although there are no specific dietary guidelines for people with lupus, there are some nutrition issues that you should know about. If any of these issues become a problem for you, talk with your doctor or nurse. They will be able to provide you with additional information and can refer you to a registered dietitian if necessary.

Weight loss or poor appetite: Weight loss over the previous year is commonly reported by people who are newly diagnosed with lupus. Weight loss and poor appetite can result from the illness itself or from some medications that may cause stomach upset or mouth sores (also called mouth ulcers).

Your doctor or nurse will assess your weight loss and other related problems and suggest changes in your diet to be sure that you are eating right and have no further weight loss.

Weight gain: This may be a problem if you take corticosteroids. These drugs often increase a person's appetite, and, unless you are careful, unwanted weight gain will occur.

Your doctor or nurse will assess your diet and other related problems and can suggest a program to help you control your weight and lose any unwanted pounds. The program will probably include a low-fat diet, exercise, and behavior modification. A registered dietitian can help you evaluate your food

likes and dislikes and eating patterns and can design a diet specifically for your needs and lifestyle.

Difficulty taking medications: Several medications can cause gastrointestinal or "GI" disturbances, such as heartburn, upset stomach, nausea, vomiting, or painful mouth ulcers.

If you are having gastrointestinal problems, tell your doctor or nurse immediately. Because many of these problems are related to how and when a medication is taken, the dose or schedule can sometimes be changed to reduce or stop the unpleasant side effects. In some cases, the doctor may change the drug. Many medications can be taken with food, which helps reduce side effects. If you have mouth ulcers, liquid forms of the drugs you are taking may be available. In addition, anesthetics for use in your mouth can decrease the pain of mouth ulcers and make swallowing easier.

Osteoporosis: This is a condition in which the bones of the body become less dense and break easily. Although this condition often affects older, postmenopausal women, it can also affect anyone who takes corticosteroids for a long period of time.

Your doctor or nurse will review your medical history, treatment plan, diet, and any risk factors you may have. Measurements of your bone density may also be taken. The most widely recognized bone mineral density test is called a dual-energy x-ray absorptiometry or DXA test. It is painless – a bit like having an x ray, but with much less exposure to radiation.

Recommendations to prevent or reduce the problem will probably include a diet high in calcium (1,000–1,500 mg/day) and vitamin D (100–500 mg/day) and an exercise plan that is appropriate for you. Calcium supplements may be prescribed by your doctor if the calcium in your diet is not enough.

Steroid-induced diabetes: Diabetes is a condition in which your body does not produce enough insulin to maintain a normal blood glucose (sugar) level. Long-term use of corticosteroids may cause diabetes, which must be treated in the same way as it is for other people with diabetes.

After a thorough physical and dietary exam, your doctor will probably place you on a special diet. You should consult with a registered dietitian who can help you understand the various aspects of the diet, and learn to plan your meals more easily. You may also have to take a drug to help keep your glucose levels within normal limits. For some people, a pill may be prescribed; for others, insulin given by injection may be necessary.

If you are diagnosed with steroid-induced diabetes, ask your doctor or nurse to refer you to a diabetes education program. These programs help newly diagnosed people with diabetes learn about their disease and manage their condition so that they continue to live a healthy and productive life. If a program is not available where you live, a registered dietitian should be able to give you the information you need.

Kidney disease: Because the kidneys are often affected by lupus, your doctor will probably order a variety of tests every so often to see how well your kidneys are working. If your doctor determines that your lupus has affected your kidneys, the goals for treating the problem will be to preserve as much kidney function as possible and prevent the condition from getting worse. Along with other treatment options, you may be placed on a low-sodium (salt), low-potassium, or low-protein diet. A registered dietitian can help you plan meals for these diets.

Cardiovascular disease: Cardiovascular complications of lupus include atherosclerosis and high blood pressure. Atherosclerosis is a condition in which fatty deposits build up on the inside of the arteries. These deposits can reduce or block blood flow. High blood pressure increases the risk of having a heart attack or stroke. High blood pressure can happen when lupus damages the kidneys, which help regulate blood pressure.

If your doctor determines that you have risk factors for atherosclerosis, you will probably be placed on a low-fat diet and an exercise plan. These will help you lower your blood cholesterol level and maintain a good body weight. If you have high blood pressure, you may be placed on a low-sodium diet, medication, or both. These will help reduce your blood pressure to within normal limits.

Sexuality and Lupus

The constant pain and fatigue associated with lupus may make it difficult to cope with the physical and emotional aspects of sex. In addition, some medications used to treat lupus can cause sexuality problems. Some of these drugs may decrease your sex drive. Other drugs may lessen sexual arousal or make it difficult to achieve an orgasm.

Some people with lupus also have a condition known as Raynaud's phenomenon. Exposure to cold causes spasms in the small blood vessels of the finger and toes. This reduces blood flow and may cause fingers and toes to turn white or blue and numb. During sex, the flow of blood increases to the genital area and decreases to other areas of the body, including the fingers. This can cause the numbness and pain of Raynaud's phenomenon to occur.

Other problems also can interfere with sexual activity, such as oral and genital sores, vaginal dryness, and yeast infections. You may feel less attractive because of skin rashes that are difficult to control.

Your partner may not understand the changes in your desire, the fact that you may feel unattractive, or the physical problems you are experiencing. He or she may think you are no longer attracted to him or her. On the other hand, you may feel your partner is avoiding you, when he or she is trying to be sensitive to your needs and is afraid of hurting you or causing you more pain during sexual contact.

These issues may be hard for you to talk about. However, a mutual willingness to have open and honest discussions with

your partner can play an important part in understanding the issues that are affecting your relationship. If the two of you cannot resolve your problems together, seek help from your doctor, nurse, or a counselor experienced in working with people who have lupus.

Caring for Yourself

- Keep a healthy attitude about yourself. Being positive can play an important part in maintaining your sexuality.
- If you notice a change in sexual desire after starting a new medication, tell your doctor or nurse.
- Ask your doctor if he or she can prescribe an anti-inflammatory or pain medication that you can take before having sex.
- Be sure you are well rested. Consider taking a nap just before sexual activity.
- Relax and ease some of the pain with a warm shower or bath just before sexual activity.
- If you have Raynaud's phenomenon, increase circulation to your fingers and toes by taking a warm bath before sex. Raising the temperature in the bedroom will also help.
- If you have vaginal dryness, use a water-based personal lubricant during sex.
- If you have a vaginal yeast infection, call your doctor so that he or she can prescribe the medication you need. Yeast infections are easily treated.
- If some physical problems make certain sexual activity difficult, don't be afraid to explore with your partner other ways to achieve mutual pleasure and satisfaction.

Additional Notes

Pregnancy and Lupus

Twenty years ago, medical textbooks said that women with lupus should not get pregnant because of the risks to both the mother and unborn child. Today, most women with lupus can safely become pregnant. With proper medical care, you can decrease the risks associated with pregnancy and deliver a normal, healthy baby.

To increase the chances of a happy outcome, however, you must carefully plan your pregnancy. Your disease should be under control or in remission before conception takes place. Getting pregnant when your disease is active could result in a miscarriage, a stillbirth, or serious complications for you. It is extremely important that your pregnancy be monitored by an obstetrician who is experienced in managing high-risk pregnancies and who can work closely with your primary doctor. Delivery should be planned at a hospital that can manage a high-risk patient and provide the specialized care you and your baby will need. Be aware that a vaginal birth may not be possible. Very premature babies, babies showing signs of stress, and babies of mothers who are very ill will probably be delivered by cesarean section.

One problem that can affect a pregnant woman is the development of a lupus flare. In general, flares are not caused by pregnancy. Flares that do develop often occur during the first or second trimester or during the first few months following delivery. Most flares are mild and easily treated with small doses of corticosteroids.

Another complication is pregnancy-induced hypertension. If you develop this serious condition, you will experience a sudden increase in blood pressure, protein in the urine, or both. Pregnancy-induced hypertension is a serious condition that requires immediate treatment, usually including delivery of the infant.

The most important question asked by pregnant women with lupus is, “Will my baby be okay?” In most cases, the answer is yes. Babies born to women with lupus have no greater chance of birth defects or mental retardation than do babies born to women without lupus. As your pregnancy progresses, the doctor will regularly check the baby’s heartbeat and growth with sonograms. About 10 percent of lupus pregnancies end in unexpected miscarriages or stillbirths. Another 30 percent may result in premature birth of the infant. Although prematurity presents a danger to the baby, most problems can be successfully treated in a hospital that specializes in caring for premature newborns.

Caring for Yourself

- Keep all of your appointments with your primary doctor and your obstetrician.
- Get enough rest. Plan for a good night's sleep and rest periods throughout the day.
- Eat a sensible, well-balanced diet. Avoid excessive weight gain. Have your obstetrician refer you to a registered dietitian if necessary.
- Take your medications as prescribed. Your doctor may have you stop some medications and start or continue others.
- Don't smoke, and don't drink alcoholic beverages.
- Be sure your doctor or nurse reviews with you the normal body changes that occur during pregnancy. Some of these changes may be similar to those that occur with a lupus flare. Although it is up to the doctor to determine whether the changes are normal or represent the development of a flare, you must be familiar with them so that you can report them as soon as they occur.
- If you are not sure about a problem or begin to notice a change in the way you feel, talk to your doctor right away.
- Ask your doctor or nurse about participating in childbirth preparation and parenting classes. Although you have lupus, you have the same needs as any other new mother-to-be.

About 3 percent of babies born to mothers with lupus will have neonatal lupus. This lupus consists of a temporary rash and abnormal blood counts. Neonatal lupus usually disappears by the time the infant is 3 to 6 months old and does not recur. About one-half of babies with neonatal lupus are born with a heart condition called heart block. This condition is permanent, but it can be treated with a pacemaker.

Planning Your Pregnancy

You and your spouse or partner should talk to your doctor about the possibility of pregnancy. You and the doctor should be satisfied that your lupus condition is under good control or in remission. Your doctor should also review potential problems or complications that could arise during the pregnancy, their treatment, and outcomes for both you and the unborn child.

You should select an obstetrician who has experience in managing high-risk pregnancies. Additional experience in managing women with lupus is also good. The obstetrician should be associated with a hospital that specializes in high-risk deliveries and has the facilities to care for newborns with special needs. It is a good idea to meet with the obstetrician before you become pregnant so that he or she has an opportunity to evaluate your overall condition before conception. This meeting also will give you the opportunity to decide if this obstetrician is right for you.

Check your health insurance plan. Make sure that it covers your health care needs and those of the baby and any problems that may arise.

Review your work and activities schedule. Be prepared to make changes if you are not feeling well or need more rest.

Consider your financial status. If you work outside the home, your pregnancy and motherhood could affect your ability to work.

Develop a plan for help at home during the pregnancy and after the baby is born. Motherhood can be overwhelming and tiring, and even more so for a woman with lupus. Although most women with lupus do well, some may become ill and find it difficult to care for their child.

After the Baby Is Born (The Postpartum Period)

Be sure your doctor or nurse reviews with you the physical and emotional changes that occur as your body returns to normal. These changes are the same as those experienced by women who do not have lupus.

Be aware that postpartum complications can arise. In addition to those that any woman who has been pregnant can experience, you might develop a lupus flare.

Try to breastfeed your baby. It is the ideal, low-cost way to provide nutrition for your baby in the first weeks or months of life. It takes time for mothers and babies to learn how to breastfeed and it may take a few weeks to get adjusted. Because breastfeeding can sometimes be

a challenge, ask your doctor or nurse for help so you do not become discouraged. Sometimes, though, breastfeeding may not be possible for the following reasons:

- A premature baby may not be able to suck adequately. Feeding your baby through a tube at first and then by bottle may be necessary. However, you may still be able to pump your breast milk for your baby.
- If you are taking corticosteroids, you may not be able to produce enough milk.
- Some medications can pass through your breast milk to your infant. It will be up to your doctor to decide whether breastfeeding is safe if you are taking any of these medications.
- Because breastfed infants tend to eat more frequently than do bottle-fed infants, breastfeeding can be very tiring. You may want to switch to a bottle and formula if breastfeeding becomes too tiring.

Be confident, though, that whichever method you choose to use to feed your baby, it will be the right decision for everyone concerned.

Before you leave the hospital, discuss birth control options with your doctor. Because it would be unwise for you to become pregnant again soon after giving birth, be sure to use an effective birth control method. **REMEMBER:** *You can get pregnant before your period begins again; also, breastfeeding and withdrawal of the penis before ejaculation are not effective birth control methods.*



Additional Notes

Nonsteroidal Anti-Inflammatory Drugs (NSAIDs)

NSAIDs are often used to reduce pain and inflammation in patients who have mild systemic lupus erythematosus (SLE). Many different types of NSAIDs exist, some of which you can buy without a doctor's prescription. These are called "over-the-counter" drugs. Examples of over-the-counter NSAIDs include aspirin, Motrin® IB, Orudis KT®, and Aleve®. Tylenol® is not an NSAID and is not used to reduce the inflammation of lupus.

Although all NSAIDs appear to work in the same way, there are differences among them. Not every NSAID has the same effect on every person. Also, you may find that one NSAID works well for a while, then for some unknown reason, it doesn't work well any more. Your doctor will probably switch you to a different NSAID to get the same helpful effects you had with the first one.

Instructions

The brand name of your NSAID is _____ .

The strength or dose of the NSAID ordered for you is _____ .

Take the NSAID _____ time(s) per day.

The best time(s) to take your NSAID:

Additional instructions: _____

Possible Side Effects

These include upset stomach, headache, ringing in the ears, dizziness, rash, itching, easy bruising, fluid retention, and blood in the stool.

Precautions

You may use NSAIDs cautiously during pregnancy, but do not take them during the first 3 months of your pregnancy or just before delivery. NSAIDs appear in breast milk and should be used cautiously if you are breastfeeding.

Some patients taking NSAIDs become more sensitive to sunlight. Use sunblock and protective clothing; avoid exposure to sunlight.

Do not take more than the recommended dose.

Do not take NSAIDs with other drugs, including over-the-counter medications, without first checking with your nurse or doctor. Over-the-counter medications are medications that you can buy without a doctor's prescription.

Recent studies of a couple of NSAIDs have suggested an increased risk of cardiovascular problems in people taking them on a long-term basis. As with any drug, it's important to weigh the benefits against the potential risk of side effects.

Tell any nurse, doctor, or dentist who is taking care of you that you are taking NSAIDs for your lupus.

Since NSAIDs can cause stomach and intestinal upset and irritation, take them with food or after meals. You should also avoid alcoholic beverages, because alcohol can aggravate these stomach and intestinal problems. Check with your doctor for guidance on these issues.

Antimalarials

Antimalarials are very effective in controlling lupus arthritis, skin rashes, mouth ulcers, and other symptoms such as fatigue and fever. They are used to manage less serious forms of systemic lupus erythematosus (SLE) in which no organs have been damaged. Antimalarials are also very effective in the treatment of discoid lupus erythematosus (DLE).

Although antimalarials may be very effective in controlling your lupus, their use takes patience. It may take weeks or months before you see any change in symptoms from the use of these drugs.

Instructions

The brand name of your antimalarial is _____.

The strength or dose of the antimalarial ordered for you is _____.

Take the antimalarial _____ time(s) per day.

The best time(s) to take your antimalarial _____

Additional instructions: _____

Possible Side Effects

These include stomach upset, loss of appetite, vomiting, diarrhea, blurred vision, difficulty in focusing, headache, nervousness, irritability, dizziness, muscle weakness, dry and itchy skin, mild hair loss, rash, change in skin color, and unusual bleeding or bruising.

Precautions

There is a small chance that antimalarials will harm a fetus. If you are considering pregnancy, your doctor may take you off the drug.

Do not take more than the recommended dose.

Do not take this drug with other drugs, including over-the-counter medications, without first checking with your nurse or doctor. Over-the-counter medications are medications that you can buy without a doctor's prescription.

Tell any nurse, doctor, or dentist who is taking care of you that you are taking an antimalarial for your lupus.

WARNING!

A possible, serious side effect of antimalarials is damage to the retina of the eye. Although this is rare with the low doses of drug that are prescribed, it is extremely important that you have a thorough eye examination before starting treatment with this drug, and every 12 months after that.

Corticosteroids

Corticosteroids are very powerful drugs that reduce inflammation in various tissues of the body. These drugs are used to treat many of the symptoms of lupus that result from inflammation. You can take them as pills or by injection. Corticosteroid creams or ointments are also available to treat skin rashes caused by lupus. Most lupus symptoms respond quickly to corticosteroids. Prednisone is a corticosteroid that is often used to treat lupus.

The decision to begin a corticosteroid is a big one and depends on your needs. Some patients may need to take the drug for a short time only, until disease symptoms get better or go away. Others with more serious or life-threatening problems may require higher doses of the drug for longer periods of time. In general, once your lupus symptoms have responded to treatment, you will gradually take less and less of the drug until you can stop completely. If it is not possible for you to stop the drug completely, your doctor will give you the smallest amount possible to keep symptoms under control.

Doctors are careful about prescribing corticosteroids because many complications are associated with taking them. As a result, it is important to take the drug exactly as prescribed. People who have been taking corticosteroids for a long time may need higher doses of the drug before, during, or after a physically stressful event, such as surgery.

Instructions

The brand name of your corticosteroid is _____.

The dose of the corticosteroid that is ordered for you is _____.

Take the corticosteroid _____ time(s) a day.

The best time(s) to take your corticosteroid: _____

You may take your corticosteroid with food or after meals if stomach upset occurs.

Additional instructions: _____

Possible Side Effects

These include changes in appearance (such as acne or increased facial hair); development of a round or moon-shaped face; thin, fragile skin that bruises easily; or movement of body fat to the trunk. You might also experience mood changes, personality changes, irritability, agitation, or depression.

Other possible side effects include increased appetite and weight gain, poor wound healing, headache, glaucoma, irregular menstrual periods, peptic ulcer, muscle weakness, osteoporosis, steroid-induced diabetes, and osteonecrosis (damage to a joint, usually the hip joint, that leads to severe arthritis).

Because corticosteroids cross the placenta, they are used cautiously during pregnancy. The drugs appear in breast milk, so if you are taking large doses, you should not breastfeed.

Avoid exposure to infections. Stay away from crowds and people known to have colds, the flu, or other infections.

Schedule regular vision checkups and report any problems with your vision to your doctor or nurse.

Talk with a registered dietitian to find out how to prevent excess weight gain and minimize certain drug effects on the body.

Do not take this drug with other drugs, including over-the-counter medications, without first checking with your nurse or doctor. Over-the-counter medications are medications that you can get without a doctor's prescription.

Tell any nurse, doctor, or dentist who is taking care of you that you are taking a corticosteroid for your lupus.

WARNINGS!

Do not take this drug if you have ever had an allergic reaction to it.

Carry medical identification and wear a bracelet to alert medical personnel that you take a corticosteroid. If you are planning to have a medical procedure, let the doctor performing the procedure know ahead of time that you take a corticosteroid. Your dose will likely need to be increased before the procedure.

NEVER MISS A DOSE

Take this drug exactly as ordered. If you do miss a dose, call your nurse or doctor immediately to find out when you should take the missed dose.

NEVER STOP THE MEDICATION SUDDENLY

Your adrenal glands, which are located just above your kidneys, normally make corticosteroids in small amounts. These corticosteroids are important for many body functions. When you take corticosteroid medication, your body begins to make much less than usual, or even stops completely. If you suddenly stop taking your medication, you may have a problem because your adrenal glands won't have had time to make the corticosteroids you need. This problem is called "adrenal insufficiency."

Signs of adrenal insufficiency include weakness, fatigue, fever, weight loss, vomiting, diarrhea, and abdominal pain. If you experience any of these problems, call your nurse or doctor immediately.

Azathioprine

Azathioprine is a drug that acts to suppress the work of the immune system. It is used mainly in organ transplantation to prevent the body from rejecting the new organ. The drug is also used in patients with lupus who have damage to their kidneys or other organs, muscle inflammation, or advanced arthritis. Azathioprine helps to reduce symptoms and damage to the affected organs. It can also help achieve a remission of the disease.

Another benefit of azathioprine is that it reduces or even eliminates the need for corticosteroid therapy. This means that patients do not have to have the unpleasant side effects that occur with corticosteroids. Immunosuppressives like azathioprine, however, can have their own serious side effects. Your doctor must work closely with you to make sure that the amount of the drug you are taking gives you the benefits you need with as few side effects as possible.

Instructions

The brand name of your azathioprine is _____.

The strength or dose of the azathioprine ordered for you is _____.

Take the azathioprine _____ time(s) per day.

The best time(s) to take your azathioprine: _____

You may take azathioprine with food if stomach upset occurs.

Additional instructions: _____

Possible Side Effects

These include stomach upset, nausea, vomiting, abdominal pain, mouth ulcers, darkened urine, pale stools, jaundice (yellowing of the skin or white portion of the eyes), unusual bleeding or bruising, and signs of infection (such as chills, fever, sore throat, or fatigue).

Precautions

Do not take more than the recommended dose.

Avoid exposure to infections. Stay away from crowds and people known to have colds, the flu, or other infections.

Do not take this drug with other drugs, including over-the-counter medications, without first checking with your nurse or doctor. Over-the-counter medications are medications that you can buy without a doctor's prescription.

Tell your nurses, doctors, or dentists that you are taking azathioprine for your lupus.

WARNING!

Use of this drug presents a definite risk to the fetus. Use an effective birth control measure during treatment and for 12 weeks after ending treatment. Azathioprine may pass into breast milk, so consult your doctor before breastfeeding.

Additional Notes

Lined area for writing notes, consisting of multiple horizontal lines.

Cyclophosphamide

Cyclophosphamide is a drug used to treat a number of cancers. It is also used for lupus treatment when major organs, such as the kidneys, are affected, and when severe inflammation has not responded to corticosteroids. In lupus, the immune system is too active. Cyclophosphamide slows down the immune system so that disease activity can be reduced.

Cyclophosphamide is a very powerful drug. It can have a number of effects on the body. As a result, it is important that you understand how it is used to treat your lupus. You will need to work closely with your doctor and nurse to make sure that the amount of the drug you are taking gives you the benefits you need with as few side effects as possible.

Instructions

The brand name of your cyclophosphamide is _____.

The strength or dose of the cyclophosphamide ordered for you is _____.

Take the cyclophosphamide _____ time(s) per day.

The best time(s) to take your cyclophosphamide: _____

Drink at least 2 quarts of water every day while taking this drug. That is equal to four big (16-oz.) glasses.

Additional instructions: _____

Possible Side Effects

These include nausea, vomiting, loss of appetite, mouth ulcers, fatigue, temporary hair loss, unusual bleeding or blood in the urine, shortness of breath, loss of menstrual periods, impotence, sterility, or signs of infection (such as increased temperature, sore throat, or flu symptoms).

Tell your nurse or doctor right away if you have any side effects.

Precautions

Do not take more than the recommended dose.

Avoid exposure to infections. Stay away from crowds and people known to have colds, the flu, or other infections.

Tell any nurse, doctor, or dentist who is taking care of you that you are taking cyclophosphamide for your lupus.

WARNING!

Do not take this drug if you suspect you are pregnant. Cyclophosphamide causes birth defects. You must use an effective birth control method while you are taking this medication. You should consider pregnancy only after treatment has been stopped and your doctor says you are healthy enough to become pregnant.

Long-term therapy with cyclophosphamide may leave a woman unable to produce eggs, or a man unable to produce sperm. This means permanent sterility. If you want to have a baby in the future, talk to your doctor about the option of storing your eggs or sperm before beginning therapy.

Methotrexate

Methotrexate is a drug used to treat cancer as well as several different rheumatic diseases. It is usually used for lupus when nonsteroidal anti-inflammatory drugs such as ibuprofen (Motrin®) or naproxen (Naprosyn®) or antimalarials such as hydroxychloroquine sulfate (Plaquenil) don't control the symptoms. Sometimes doctors prescribe it to control lupus during flares or times of increased disease activity. It works by suppressing the immune system, which is overactive in lupus.

Methotrexate works slowly, so it may take a few weeks before you notice its benefits. Although methotrexate is generally safe at the doses prescribed for lupus, it is still a powerful drug. It is important that you understand exactly how and when to use this drug, and what the potential side effects are. You will need to work closely with your doctor and nurse and undergo regular lab tests to make sure that the amount of the drug you are taking gives you the benefits you need with as few side effects as possible.

Instructions

The brand name of your methotrexate is _____.

The strength or dose of the methotrexate ordered for you is _____.

Take the methotrexate _____ time(s) per week.

The best time(s) to take your methotrexate: _____.

Take methotrexate pills with milk or food. Methotrexate injections should be given just beneath the skin on the thigh or abdomen unless your doctor advises otherwise.

Possible Side Effects

These include diarrhea, dizziness, hair loss, mouth ulcers, nausea and vomiting, and rashes or itching skin. Tell your nurse or doctor right away if you have any side effects.

Precautions

Do not take more than the recommended dose. Before starting methotrexate, let your doctor know if you drink alcohol or if you are taking other medications, including antibiotics, anti-inflammatories, asthma medications, or drugs that suppress the immune system.

Avoid exposure to infections. Stay away from crowds and people known to have colds, the flu, or other infections. Report any signs of infection to your doctor immediately.

Do not have immunizations while taking this drug without first checking with your doctor.

WARNING!

Do not take this drug if you suspect you are pregnant. Methotrexate can be dangerous to unborn babies. You must use an effective birth control method while you are taking this medication. You should consider pregnancy only after treatment has been stopped and your doctor says you are healthy enough to become pregnant.

Cyclosporine

Cyclosporine is a drug that was originally developed to prevent organ rejection in people who had undergone transplants. Today, it is used in the treatment of a number of inflammatory diseases, including rheumatoid arthritis, psoriasis, and lupus.

Cyclosporine is a powerful drug. It can have a number of effects on the body, including high blood pressure and kidney and liver problems. As a result, it is important that you understand how it is used to treat your lupus. You will need to work closely with your doctor and nurse to make sure that the amount of the drug you are taking gives you the benefits you need with as few side effects as possible.

Instructions

The brand name of your cyclosporine is _____.

The strength or dose of the cyclosporine ordered for you is _____.

Take the cyclosporine _____ time(s) per day.

The best time(s) to take your cyclosporine: _____.

Take cyclosporine at the same time(s) each day.

Additional instructions: _____

Possible Side Effects

These include acne or oily skin; bleeding, tender, or enlarged gums; frequent need to urinate; headaches; high blood pressure; increased hair growth; kidney problems; leg cramps; nausea; trembling and shaking of hands.

Tell your nurse or doctor right away if you have any side effects.

Precautions

Do not take more than the recommended dose.

Avoid exposure to infections. Stay away from crowds and people known to have colds, the flu, or other infections. Let your doctor or nurse know if you experience symptoms of infection.

Tell any nurse, doctor, or dentist who is taking care of you that you are taking cyclosporine for your lupus.

WARNING!

Do not eat grapefruit or drink grapefruit juice while taking this medication. Either can increase your risk of side effects by increasing the amount of cyclosporine in your body.

Additional Notes

Mycophenolate Mofetil (CellCept®)

Mycophenolate mofetil (CellCept®) is a drug that was developed to suppress the immune system, thereby preventing the rejection of transplanted organs. It is also used in lupus to slow down the immune system, particularly if inflammation threatens internal organs such as the kidneys.

CellCept® is a powerful drug. It can have a number of effects on the body. As a result, it is important that you understand how it is used to treat your lupus. You will need to work closely with your doctor and nurse and undergo regular lab tests to make sure that the amount of the drug you are taking gives you the benefits you need with as few side effects as possible.

Instructions

The strength or dose of the CellCept® ordered for you is _____.

Take the CellCept® _____ time(s) per week.

The best time(s) to take your CellCept®:

Take your medication at the same time(s) each day. Swallow tablets whole with a full glass of a water.

Additional instructions: _____

Possible Side Effects

These include abdominal pain, constipation, diarrhea, fever, headache, high blood pressure, nausea, respiratory infection, swelling of hands and feet, and urinary tract infection.

Tell your nurse or doctor right away if you have any side effects.

Precautions

Do not take more than the recommended dose.

Avoid exposure to infections. Stay away from crowds and people known to have colds, the flu, or other infections. Let your doctor or nurse know if you experience symptoms of infection.

Tell any nurse, doctor, or dentist who is taking care of you that you are taking CellCept® for your lupus.

WARNING!

CellCept® can never be taken during pregnancy.

Intravenous Immunoglobulins (IVIGs)

Intravenous immunoglobulins or IVIGs are proteins in the blood plasma that act as antibodies. The immunoglobulins your doctor will give you are pooled from blood donors who have been screened for blood-borne diseases. They have also gone through a cleaning process to ensure they are not contaminated.

Immunoglobulins can be used to treat organ involvement with lupus or vasculitis (inflammation of blood vessels).

IVIGs are always infused in an outpatient infusion center, so you won't have to fill a prescription at your local pharmacy or remember to take the medication at home. But it is important to understand what to expect from the procedure in order to make the most of it and minimize side effects.

Infusions may last from a few hours to all day, depending on your individual response.

Instructions

The strength or dose of the IVIG your doctor has ordered is _____.

Your infusions are scheduled for: _____

Additional instructions: _____

Possible Side Effects

These include back pain, fast heartbeat, headaches, joint and muscle pain, nausea and vomiting.


Precautions

IVIGs can cause severe headaches that can get worse for a day or two after the infusion until they start to subside. Sometimes medications can minimize IVIG-related headaches. If you experience a headache following the procedure, ask your doctor to prescribe something for pain. Also, let your doctor or nurse know immediately if you experience any signs of an allergic reaction such as itching, hives, swelling of the eyes and face, difficulty breathing, or wheezing.

Chapter 8

Resources, Bibliography,
and Index





Nurses and other health professionals may find the following organizations and written materials useful as sources of further information about lupus and patient care for the disease.



Resources

National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)

The mission of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), a part of the Department of Health and Human Services' National Institutes of Health (NIH), is to support research into the causes, treatment, and prevention of arthritis and musculoskeletal and skin diseases; the training of basic and clinical scientists to carry out this research; and the dissemination of information on research progress in these diseases. The NIAMS Information Clearinghouse is a public service sponsored by the NIAMS that provides health information and information sources. Additional information can be found on the NIAMS Web site at www.niams.nih.gov.

1 AMS Circle
Bethesda, MD 20892-3675
Phone: 301-495-4484 or
877-22-NIAMS (226-
4267) (free of charge)
TTY: 301-565-2966
www.niams.nih.gov

National Institute of Nursing Research

The National Institute of Nursing Research (NINR), a component of NIH, supports research and research training in universities, hospitals, research centers, and at NIH in areas related to health promotion and disease prevention, managing the symptoms and disabilities of illness,

and improving the environment in which patient care is delivered. Chronic diseases, such as lupus and arthritis, are among the six major areas of emphasis for the Institute. For more information on the Institute and its programs, contact the NINR Office of Science Policy and Public Liaison at:

31 Center Drive
MSC 2178
Building 31, Room 5B10
Bethesda, MD 20892
Phone: 301-496-0207
www.ninr.nih.gov

American College of Rheumatology's Association of Rheumatology Health Professionals

The American College of Rheumatology (ACR) is an organization of doctors and associated health professionals who specialize in arthritis and related diseases of the bones, joints, and muscles. The Association of Rheumatology Health Professionals (ARHP) is a division of ACR. The ARHP aims to enhance the knowledge and skills of rheumatology health professionals and to promote their involvement in rheumatology research, education, and quality patient care. The Association also works to advance and promote basic and continuing education in rheumatology for health professionals who provide care to people with rheumatic diseases. For more information, contact ARHP at:

1800 Century Place
Suite 250
Atlanta, GA 30345-4300
Phone: 404-633-3777
www.rheumatology.org

Arthritis Foundation

The Arthritis Foundation is the major voluntary organization devoted to supporting arthritis research and providing educational and other services to individuals with arthritis. It publishes free pamphlets and a magazine for members on all types of arthritis. It also provides up-to-date information on research and treatment, nutrition, alternative therapies, and self-management strategies. Chapters nationwide offer exercise programs, classes, support groups, physician referral services, and free literature. For more information, call your local chapter, listed in the white pages of the phone book, or contact the Arthritis Foundation at:

P.O. Box 7669
Atlanta, GA 30357-0669
Phone: 404-965-7888 or
800-568-4045
www.arthritis.org

Lupus Foundation of America

The Lupus Foundation of America (LFA) is the main voluntary organization devoted to lupus. LFA assists local chapters in providing services, including education, referrals, and support groups, to people with lupus; works to educate the public about lupus; and supports lupus research. For more information, contact LFA at:

2000 L Street, NW, Suite 710
Washington, DC 20036
Phone: 202-349-1155 or
800-558-0121
www.lupus.org

SLE Foundation, Inc.

The SLE Foundation supports and encourages medical research to find the cause and cure of lupus, and improve its diagnosis and treatment. It also provides a wide variety of services to help people with lupus and their families. In addition, this voluntary organization conducts a broad-based public education program to raise awareness of lupus, and increase understanding of this serious chronic autoimmune disease. For more information, contact the SLE Foundation at:

330 Seventh Avenue, Suite 1701
New York, NY 10001
Phone: 212-685-4118 or
800-74-LUPUS
www.lupusny.org



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