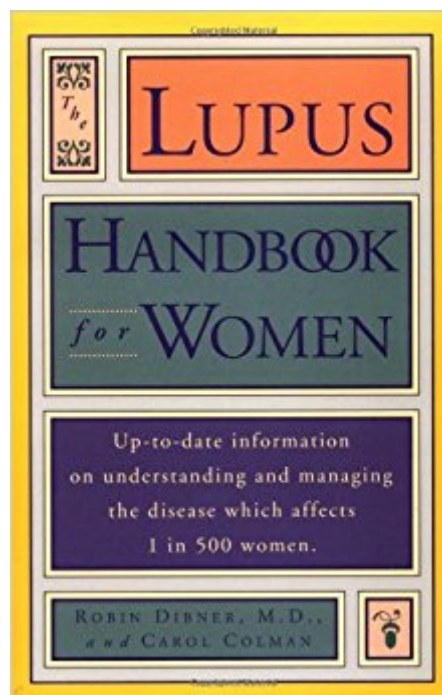




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# Lupus Handbook For Women: Up-to-Date Information On Understanding And Managing The Disease Which Affects



## Synopsis

A complete Guide for Women with Lupus The Lupus Handbook for women provides all the information a woman needs to understand the disease, its diagnosis, and the treatment. It will answer her questions and help her to work with her doctor in managing the disease. Rheumatologist Dr. Robin J. Dibner, in clear and supportive terms, tells women what they need to know, including: \*

- \* What lupus is, how it affects the body, and why women are particularly vulnerable to it (90 percent of Americans with lupus are women)
- \* The three different types of lupus (discoid lupus, systemic lupus erythematosus [SLE], and drug-induced lupus)
- \* How to get a correct diagnosis and understand the tests (because the symptoms are often mistaken for those of other illnesses, it can take three to five years to get a definitive diagnosis)
- \* The pros and cons of the various conventional drugs and therapies
- \* What the new, experimental treatments are, whom they are for, and what their risks and benefits are
- \* How to use stress control, diet, and exercise to prevent flare-ups and maintain health
- \* How to keep lupus from interfering with a normal dating and sex life and with the development of healthy relationships
- \* How to have a safe, though high-risk, pregnancy

The Lupus Handbook for Women also includes information on the major lupus research centers, support groups, and other sources of help and information.

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## Customer Reviews

Robin Dibner, M.D, is a clinical rheumatologist. She is the Associate Director, Department of Medicine, and Medical Residency Program Director, at Englewood Hospital and Medical Center in

Englewood, New Jersey. Dr. Dibner is also Assistant Clinical Professor, Department of Medicine, Mount Sinai School of Medicine in New York City.

Chapter 1 What Is Lupus? At one time, lupus was considered a rare disease, but, thanks to better diagnostic techniques and greater awareness on the part of physicians, we now know that it is far more common than we ever thought. About five hundred thousand Americans have lupus, and more than 90 percent of these are women. About sixteen thousand new cases are diagnosed each year. (Asian, African-American, and Hispanic women appear to be at somewhat higher risk for lupus than Caucasian women.) Notably, lupus is more widespread than many better-known diseases, such as leukemia or multiple sclerosis. Lupus typically strikes women of childbearing age -- usually between fifteen and forty -- however, it can also occur in very young girls and postmenopausal women. In rare cases, infants of mothers with lupus or other connective tissue diseases may be born with neonatal lupus, a transient form of the disease that usually disappears within six months.

I woke up one morning with a strange pain shooting from my neck down to my shoulders. I felt a lot more tired than usual. I went to see my doctor who decided to test me for "the Three L's": Lyme disease, lupus, and leukemia. The tests were negative for all three, so he decided to treat me for Lyme and put me on very high doses of antibiotics. I went away on vacation and did a lot of sunbathing. I got a bright red rash all over my face, even in my scalp, and I was sore and puffy everywhere. When I came back, I went to another doctor, this time a rheumatologist, who took one look at me and said, "You don't have Lyme disease, you have lupus."

Sarah, thirty-three I was feeling ill with all kinds of funny symptoms. I'm normally very active, but I felt exhausted. It was a weird kind of exhaustion. No matter how much I slept, I still felt tired. I felt achy, I had floating arthritis. A joint would hurt one day, and then another joint would hurt the next day. Another strange thing -- I couldn't close my jaw. It felt as if my dentist had put a filling in the wrong way. I went to an orthopedist and he said, "Well, you must have strained yourself lifting something." I went to another doctor, who tested me for Lyme, and I tested positive. My brother, who is a doctor, didn't believe that I had Lyme. He sent me to a rheumatologist, who ran all kinds of tests. She finally told me that I had lupus.

Claire, fifty-one All through high school I was sick. I had seizures, and my parents were told that I had some kind of seizure disorder. In my twenties, I began developing strange neurological symptoms. I thought I was having a nervous breakdown. I had difficulty focusing for very long periods at a time, and I had strange feelings in my head. I went to a doctor who suggested that I see a psychiatrist. I went to a psychiatrist, and after talking with me, he said that I was totally sane but terribly sick. He referred me to a rheumatologist, who told me that I was having a lupus flare.

Susan, thirty-seven These three

women experienced vastly different symptoms. Yet, all three have been diagnosed with the same disease: systemic lupus erythematosus (SLE), commonly called lupus, a chronic, inflammatory disease that can affect any part of the body. Like many other women with lupus, these women were initially misdiagnosed and had to go from doctor to doctor before getting the correct diagnosis, usually from a rheumatologist. Their experiences are echoed by hundreds of other patients. In fact, it is the rare lupus patient who gets diagnosed quickly. Although there is a growing awareness about lupus within the medical community as well as among laypeople, a great deal of ignorance remains. Many cases go undetected or are misdiagnosed. Part of the problem may stem from the lack of emphasis on diseases such as lupus in general medical education. Lupus is very complicated, and because it is such a varied disease, it may be difficult to pigeonhole for medical students. In the past, rheumatology was covered only briefly in medical school, and lupus may have been discussed in only one or two lectures (if at all) and usually only in connection with kidney disease. Although many medical schools now include more on rheumatology in their curricula, the American College of Rheumatology (the professional organization of rheumatologists) has deemed it necessary to develop curricular materials to promote more in-depth coverage of rheumatology in medical school. To add to the general lack of awareness, lupus is not the kind of disease that captures the constant attention of the media the way that acquired immunodeficiency syndrome (AIDS) and to a lesser extent breast cancer and Lyme disease have. Although it is not known exactly how lupus is contracted, it is believed that it is not contagious. Thus, public health officials do not feel that it is necessary to bombard the media with information on how to prevent lupus as they do with AIDS or Lyme, because as far as we know, lupus cannot be prevented. Second, unlike breast cancer, lupus cannot be detected through a simple test such as a mammogram. In fact, there is no single diagnostic test for lupus. And since women are not routinely screened for lupus, it is not a disease that is on the minds of most patients or even their physicians. Lupus is also primarily a woman's disease. Historically, diseases that afflict women have been neglected by the medical establishment. In fact, to compensate for this neglect, the National Institutes of Health have recently mandated that women must be included in all research studies. Currently, in comparison to other "women's diseases," however, lupus has received more attention from researchers because of its link to the immune system, which is an area of science that has received much attention in recent years. Even so, there are few controlled clinical trials involving human subjects, and much more research is required in this and other areas pertaining to women's health. Because most lupus patients are women, there is a risk that physicians may not take their complaints as seriously as they do those of male patients. Many women with lupus say that their complaints, at least initially,

were dismissed by their physicians as unimportant. In some cases, vague symptoms such as fatigue or general achiness are quickly labeled psychosomatic, especially if the patient is female. The medical establishment has a long history of dismissing women's symptoms as "hysterical" or "neurotic," and there are many studies that document that this attitude may still prevail. However, I believe that ignorance and sexism are not the primary reasons why women with lupus frequently have difficulty getting a correct diagnosis. In fact, the real culprit may be the quirky nature of the disease itself. There is no typical case of lupus. In some women, lupus may begin as a rash -- often triggered by sun exposure -- and quickly develop into serious kidney disease. In others, lupus may cause fatigue and arthritis. In others, lupus causes chest pain, hair loss, or cold hands and feet. In still others, seizures and Alzheimer's-type symptoms may be present. In many cases, patients may have difficulty articulating their symptoms because they cover such a broad range. When asked what's wrong, they often reply, "Everything hurts," or "I feel achy all over." They may be accurately describing how they feel, but this kind of vague response can confuse physicians or make them wonder whether the patient is overreacting. (Those of us who routinely treat lupus patients understand that our patients really do hurt all over.) The diversity of lupus symptoms is mind-boggling, and as I mentioned earlier, to complicate matters even further, there is no one medical test that can positively confirm a diagnosis of lupus. Lupus can easily be mistaken for other diseases, such as Lyme (for which lupus patients often test false positive), chronic fatigue syndrome, and even depression. In fact, to clarify which patients should be considered to have lupus, the American College of Rheumatology developed a list of eleven criteria. A patient fulfilling four or more criteria usually has lupus. (These criteria are discussed in Chapter 2, see p. 27.)

**THE COMMON LINK** Although every case of lupus is different, there is one common link: the immune system. Lupus is an auto(self)immune disease. This means that the strange and disparate symptoms characteristic of this disease are caused by a malfunction of the patient's own immune system. In a normal immune system, the body produces substances called antibodies to fight against germs or toxins (antigens) that could cause disease. These antibodies are usually careful to attack only the unwelcome invaders without harming healthy tissue. In lupus, however, the immune system becomes hyperactive: It begins producing excess quantities of antibodies that are directed against the body's own tissues -- autoantibodies. Depending on the severity of the disease, these autoantibodies and cells that are part of the immune system attack different parts of the body. For example, some autoantibodies may be directed against the bone marrow, inhibiting production of red blood cells, which can cause severe anemia. Others can form substances called immune complexes, which can cause inflammation and damage many parts of the body. Connective tissue

-- materials between the bone and the muscles, including tendons, collagen, and cartilage -- appears to be especially vulnerable to inflammation. Even major organ systems, including the heart, lungs, kidneys, eyes, and brain, can be damaged by these immune or inflammatory processes. Although a hyperactive immune system seems to be the common link among lupus patients, that is where the similarity ends. Some patients produce a large quantity of different antibodies, others produce very few antibodies. In fact, to add to the complexity, there is often no clear connection between the amount or type of antibodies that are produced and the severity of the symptoms.

**THE DIFFERENT FORMS OF LUPUS** The term lupus refers to three different autoimmune diseases: discoid, SLE, and drug-induced lupus.

**DISCOID LUPUS** Discoid lupus is a skin disease that is characterized by a rash that usually appears on the face, neck, and scalp and inside the ears. In most cases, discoid lupus does not cause other symptoms and does not affect any internal organs. However, if untreated, it can cause permanent scarring and baldness. About 10 percent of all cases of discoid lupus will develop into a mild form of SLE.

**SYSTEMIC LUPUS ERYTHEMATOSUS** SLE, the most serious form of this disease, may involve the skin, joints, and tendons (connective tissue) as well as other body organs. Because of the involvement of connective tissue, SLE is often referred to as a connective tissue disease. However, lupus is also called a collagen vascular disease because inflammation of the blood vessels, vasculitis, is a common complication.

**DRUG-INDUCED LUPUS** Certain drugs, notably hydralazine, which is used to treat hypertension, and procainamide, which is used to treat irregular heartbeat, can trigger lupus attacks in people who have no history of the disease. Usually, once the drug is discontinued, the symptoms gradually disappear. There is a genetic predisposition for drug-induced lupus, which is related to the way that medication is metabolized in the body.

**THE PROGNOSIS IS GOOD** When the doctor said I had lupus, my mother cried. She had an aunt who had died very young from lupus many years ago. My doctor said that, for one thing, things had gotten a lot better and, for another, we shouldn't believe any horror stories that we heard about lupus. Just because something bad happened to someone else doesn't mean that my case is going to be like hers. As it turned out, my case has been pretty mild.

Kelly, twenty-nine Until recently, SLE -- the most serious form of this disease -- was considered fatal. A famous study conducted at Johns Hopkins University in the 1950s revealed that less than 50 percent of all lupus patients were alive after a mere four years following diagnosis. In recent years, that grim prognosis has dramatically changed for the better. Although lupus is a chronic disease and there is no cure, there are now a wide variety of highly effective treatments. In fact, depending on the study, it has been found that anywhere from 76 to 90 percent of all patients diagnosed with lupus will live ten years or more after diagnosis, and many will live normal life spans.

With good medical care, most will have mild cases and live fairly normal lives. In most cases, even those who have severe recurrent attacks, or "flares," can be managed successfully. Unfortunately, women of lower socioeconomic groups have the worst prognosis, possibly related to their limited access to appropriate care.

**THE CAUSES OF LUPUS** For centuries, the medical community has been baffled by this atypical and unpredictable disease. Unlike infectious diseases such as AIDS or Lyme, which are transmitted in specific ways, we don't know why or how people develop lupus or even why it is more common among women than men. We do believe that lupus is not contagious. We're not even sure if all the different symptoms that we label as lupus are actually caused by the same thing. Although we are far from having all the answers, we do have some intelligent theories about the possible causes of this disease. Hippocrates may have been the first physician to describe lupus when he referred to a mysterious rash that appeared on the cheeks and nose in a distinctive pattern. The skin disease was named lupus in 1851 by a French physician who, believing that the bright red rash resembled the bite of a wolf, dubbed the disease lupus (Latin for wolf) erythematosus (Latin for red). In 1895, a renowned physician, Sir William Osier, recognized that some forms of lupus involved more than just a rash and actually affected internal organs, and he added the word systemic to the name.

**THE IMMUNE SYSTEM** Very little was known about the possible causes of lupus until 1957, when researchers discovered the presence of autoantibodies in the blood of lupus patients. The discovery was provocative: Researchers now knew that a malfunction of the immune system was somehow involved in the disease process, but they still didn't understand the precise mechanism. Through the years, further study of immunity has shed some light on the workings of this complex and intricate system. Researchers now believe that the defect in the immune system that triggers the production of autoantibodies may be a result of a breakdown in communication between specific cells. Here is a much simplified explanation of their findings. Certain white blood cells called lymphocytes are key players in the production of antibodies. The B lymphocytes produce antibodies as the body needs them. Some T lymphocytes are called the helper cells because they promote immune responses and encourage the B lymphocytes to produce more antibody, and different T lymphocytes, known as suppressor cells, inhibit immune responses and tell the B lymphocytes that it is time to cut back on production. Some researchers believe that for an unknown reason, in active lupus, the suppressor T cells fail to keep the brakes on the producer B cells, which throws the entire immune system out of balance and leads to the reckless production of autoantibodies. Interestingly enough, studies show that during active phases of the disease, lupus patients do not produce enough suppressor T cells. However, during the inactive phases, or times of remission, they have a normal amount of suppressor cells.

The immune system is extraordinarily complicated, and we still have much to learn about the mechanisms within the immune system that go awry causing lupus. At this point, we can only speculate as to why it happens. The current belief is that lupus may be caused by the complex interaction between several factors, including a genetic predisposition and specific environmental triggers.

**GENETICS** There appears to be a genetic predisposition to develop lupus as well as other similar autoimmune diseases. However, the genetic link is somewhat complicated. About 10 percent of all cases of lupus are familial, that is, the patient has a close relative (parent or sibling) who also has lupus. Only 5 percent of children born to a parent with lupus will actually develop lupus. Research shows that people with particular genetic tissue types called human leukocyte antigen (HLA types) are more prone to develop lupus than those with other types. (Tissue types can be determined by a blood test.) HLA is genetically determined and related to immune function. There is also an increased incidence of lupus among identical twins (twins with the same genes), but only a slightly increased risk among fraternal twins, who are no more genetically connected than any other pair of siblings. Interestingly enough, there is a somewhat higher rate of lupus among nonrelated members of the same household, such as stepsisters, than in the general population, which suggests that environmental triggers may also play a role. However, there is even a greater risk of nonrelated members of the same household developing autoantibodies without necessarily developing lupus. This also suggests that some environmental factor -- a virus, perhaps, or exposure to some chemical or medication -- may trigger the production of autoantibodies. It seems likely though that only individuals who are genetically predisposed to lupus may actually develop the disease.

**INFECTION** Many researchers strongly suspect that some as-of-yet unidentified infection may be responsible for the breakdown in communication between the T-helper cells and the B lymphocytes. We know that another disease that afflicts the immune system -- AIDS -- is caused by the devastating effect of a human immunodeficiency virus (HIV) that deactivates the immune system. It seems logical that a disease that has just the opposite effect on the immune system, which makes it hyperactive, may also be caused by a viral infection.

**HORMONES** Many doctors believe that there is a connection between the female hormone estrogen and lupus, although we don't know exactly what it is. We do know that lupus tends to strike women at a much higher rate than men, usually after puberty when female hormone levels rise. We also know that high-estrogen birth control pills can trigger a flare in some women and that some women may experience flares during pregnancy, when all levels of female hormones, including estrogen, are higher than normal. Several studies have shown that neither men nor women with lupus metabolize or break down estrogen in the same way as people without lupus. Other studies have shown that estrogen may



somehow activate the immune system, while androgens (male hormones) may somehow deactivate the immune system. Finally, studies involving strains of mice prone to lupus demonstrate that female mice develop lupus earlier than male mice and have more severe cases. Related studies show that if the testes of male mice are removed, they will develop lupus earlier, whereas if the level of their male hormones is raised, the onset of lupus is delayed. As of yet, no one has conclusively found the link between estrogen and lupus, but it certainly bears further study.

### THE SILICONE CONTROVERSY

Recently, there has been much publicity suggesting that breast implants made of silicone gel may trigger autoimmune diseases in women, including lupus, rheumatoid arthritis, and scleroderma, a connective tissue disease characterized by the thickening of the skin. Researchers have found that after silicone breast implantation, some women developed autoantibodies and/or symptoms of connective tissue disease. Moreover, it appears as if women who had ruptured implants or implants that leaked experienced symptoms sooner and more severely than those whose implants remained intact. It is still unclear as to whether the silicone gel actually triggered these abnormalities or whether these women would have developed these problems anyway and the silicone merely accelerated the process. A third possibility is that these women would have developed autoimmune diseases whether or not they had implants. Until further studies can solve this mystery, many physicians believe that breast augmentation of any kind should be approached with extreme caution.

### THE SYMPTOMS OF LUPUS

Although every woman with lupus may experience the illness in a different way, there are some common symptoms.

- \* **Fatigue.** Of all the symptoms of lupus, fatigue is the most universal. Patients don't just complain about being tired, they talk about a form of deep exhaustion that interferes with their ability to function at anywhere near normal levels. I often hear things from patients like, "I used to be able to walk for miles, now I have to sit down after one block," and "I never used to take naps in the afternoon, now I can't get through the day if I don't." Many rheumatologists now believe that the fatigue and achiness in some lupus patients is compounded by another condition called fibromyalgia. This is a poorly understood syndrome characterized by fatigue, diffuse achiness, and certain characteristic tender points on physical examination. Although fibromyalgia syndrome is also seen in nonlupus patients, recent studies show that it may be present in nearly half of all lupus patients.
- \* **Pain.** Patients often complain of almost flulike aches and pains all over their bodies. In some cases, patients describe a feeling similar to the muscle soreness that may occur after a vigorous workout. Some patients have arthritis, specific pain, and/or swelling in their joints, usually in the smaller joints in the hands and feet. Very often, they may wake up feeling stiff and uncomfortable. The pain may subside during the day and worsen at night.
- \* **Rashes.** A variety of rashes can be seen in lupus, but the most common

is a red facial rash called malar or butterfly rash. \* Sun sensitivity. A majority of women with lupus will have some symptoms (rash, fever, or achiness) after intense sun exposure. \* Hair loss. During periods of active disease, patients may notice more hair on their pillow when they get up in the morning or more hair in the shower drain. Patches of hair loss may also be noted. \* Fever. Some women with lupus run a low-grade fever of around 100 degrees all the time, and some develop a high fever that may come and go. The fever may increase at night. \* Chest pain. A sharp pain caused by the inflammation of the lining of the heart or lungs is a common symptom of lupus. \* Cold hands and feet. About 20 percent of all women with lupus have Raynaud's syndrome, a sensitivity to cold in the fingers and often the toes. When exposed to cold, the fingertips can turn white and the nail beds can turn a bluish color. When rewarmed, the fingers become red. Raynaud's can be very uncomfortable, causing a deep, tingling feeling in the hands and feet. Emotional stress can also trigger episodes. \* Depression. Many lupus patients experience a severe, organic depression characterized by a sense of helplessness and hopelessness. \* Edema or swelling. For some patients, the first sign of lupus may be swelling in the ankles and legs or around the eyes. Swelling can be a sign of kidney disease caused by the lupus. \* Easy bruising. Patients may notice that they bruise more easily, a sign of low platelet count (platelets are clotting cells that may be destroyed by autoantibodies). \* Dry eyes, dry mouth. Many women with lupus have Sjogren's syndrome, in which autoantibodies attack the glands that produce saliva and other lubricants. \* Premenstrual flares. Many women report that whatever symptoms they have get worse right before their periods.

**MANAGING LUPUS** Although lupus cannot be cured, it can be managed, most often quite successfully. The patients who fare the best -- physically and emotionally -- are the ones who, early on, become active partners with their physicians in managing their illness. Before this goal can be achieved, patients must come to terms with having lupus. When someone is diagnosed with a chronic disease, the initial reaction is typically one of denial and anger. This is particularly true for many newly diagnosed women with lupus, who, as young adults, are planning on pursuing careers and starting families and do not want to be hampered by the physical constraints of chronic illness. There's a tendency to think, If I just ignore this, it will go away. However, in the case of lupus, denying symptoms such as fatigue, pain, and fever can be a terrible mistake. Prompt medical attention can often mean the difference between controlling the illness early on or developing a major flare. There are several steps that a patient must take in order to effectively manage her disease. \* Educate yourself. Knowledge is empowering. Learn about lupus. Contact the Lupus Foundation, the Arthritis Foundation, or any other resource group that can enhance your understanding of what's happening to your body (see Resources for addresses and phone

numbers). An educated patient will be able to talk with her physician on a more sophisticated level and, more important, will be better prepared to be involved in the critical decisions about appropriate treatment. \* Develop self-awareness. Learn to know yourself. Become sensitive to your body. In particular, learn to recognize what's normal and what's not. It's your responsibility to report any significant change in symptoms to your physician as promptly as possible. (For more information, see Chapter 5.) \* Avoid self-blame. Patients need to learn that there are things that they can control, like maintaining a healthy lifestyle, watching for any unusual symptoms, and complying with their treatment regimens. However, even the most conscientious of patients can have a flare. I have seen too many women who have taken excellent care of themselves suddenly get ill and then blame themselves. They rack their brains, trying to figure out what they ate or what they did that could have triggered the flare. They are putting themselves through unnecessary grief. Some lupus patients suddenly flare for no apparent reason. No one is to blame, least of all the patient. You simply have to accept the fact that this disease is unpredictable and conserve your energy for getting better. \* Dream your dreams. You have a chronic disease that may require special attention, but your life is far from over. Although your disease is part of your life, it is not all of your life. Lupus notwithstanding, if you are truly motivated to do something, you should at least try to do it. There may be times when your illness interferes with your progress; dreams may have to be postponed or even modified. But I guarantee that you will bounce back faster and survive the challenges of chronic illness better if you keep your goals and dreams alive. Copyright © 1994 by Robin Dibner, M.D., and Carol Colman

I was overwhelmed when I got my diagnosis of lupus over 2 years ago, so my mom purchased this book for me and it really helped me to understand exactly what this disease does and how I, as a woman, can deal with it. I actually have a pretty severe form of Lupus and I still refer to this handbook a lot, especially when a new symptom pops up. It has also helped my dad, mom, sister, boyfriend, and friends to understand what Lupus is and what I'm going through. So if you are a woman with Lupus, especially if you are newly diagnosed, or if a woman in your life has Lupus, read this book.

I'm not done with this book. If you are newly diagnosed with any form of Lupus or you LOVE someone with Lupus. This book is GREAT and very informative!! Also take it to your doctors so you can let them know that you're keeping up with YOUR OWN health!!

My mom has lupus so I bought this book for her and she reads it and loves it. It has helped her through so much with everything she is going through from treatments to fighting her anxiety of everything and stress. This is a great book for women struggling with Lupus.

I borrowed this book from the library and I just had to buy it. I have read a lot about lupus since my diagnosis 4 years ago. This is the most useful resource I have found yet. It explains the disease and possible causes, and also gives information on the tests that lupus patients routinely undergo.

Very helpful. Lots of information. Nice to have it all in one book to refer to.

I have found this book to be informative and helpful and refer to it often for help with a family member with Lupus.

I ordered it for my Daughter, and she got a lot of good info out of this book Hopefully it will help her Lupus

These books on lupus were bought for a friend who recently was diagnosed with lupus. They are helping her understand what is happening to her body. They were great choices.

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