

# Autoimmune Diseases

If you have an autoimmune (aw-toh-ih-MYOOON) disease, your experience may have been frustrating and confusing. It can be hard to describe the often debilitating symptoms many people endure. And the medical community is still learning about these diseases, which affect mostly women. To date, there are no cures.

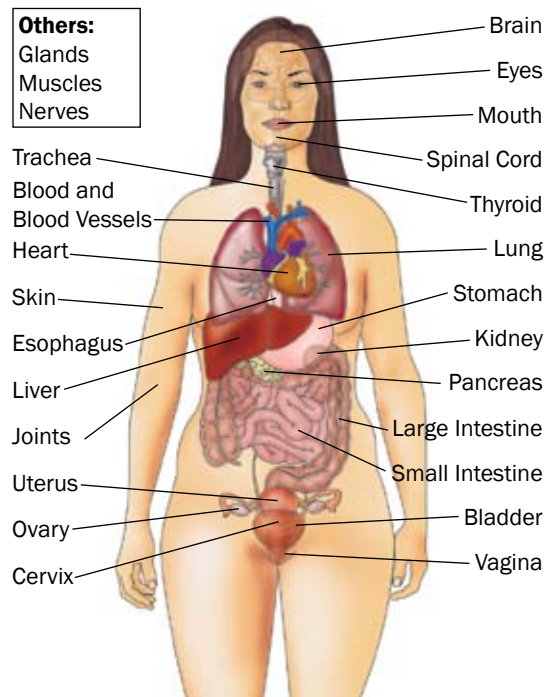
The good news is that there are treatments available to manage tough symptoms and you can feel better. At the same time, experts are working toward better treatments and perhaps even a way to prevent these diseases someday.

## What are autoimmune diseases?

The immune system is a complex network of special cells and organs that defends the body from “foreign” invaders. These invaders can be germs, viruses, and other foreign things called antigens (AN-tih-juhnzh).

At the core of the immune system is the ability to distinguish between self and nonself: what’s you and what’s foreign. A flaw can make the body unable to tell the difference between self and nonself. When this happens, the body makes autoantibodies (AW-toh-AN-teye-bah-deez) that attack normal cells by mistake. At the same time, special cells called regulatory T cells fail to do their job of keeping the immune system in line. The result is a misguided attack on your own body. This causes the damage we know as an autoimmune disease.

## Body Parts That Can Be Affected by Autoimmune Diseases



The more than 80 different autoimmune diseases are each defined by the kind of damage involved and the body part(s) affected. The blood, skin, eyes, nerves, and heart are just some of the body parts that can be involved.

### **Who is at risk of getting autoimmune diseases?**

Individually, autoimmune diseases are rare. Together, they are a leading cause of disability and death. The number of people with autoimmune diseases is growing, but it is unclear why. It is also unclear why certain people are at greater risk of getting these diseases. To learn more, experts are studying patients to see what they may have in common.

**Women of childbearing age.** Of the more than 23.5 million people with autoimmune diseases, most are women. As a group, these diseases are a leading cause of death among young and middle-aged women. Often, they strike during childbearing years when women are likely juggling multiple roles as mothers, caregivers, employees, friends, community members, and much more. Dealing with an autoimmune disease can be a trying experience on top of an already busy life.

Hormones are thought to play an important role because some autoimmune diseases “act” differently during pregnancy, menstruation, and menopause. Hormone changes at these times can cause symptoms to either get worse or better, depending on the disease. For instance, rheumatoid arthritis (ROO-muh-toid ar-THREYE-tuhss) improves during pregnancy, whereas systemic



lupus erythematosus (LOO-puhss ur-ih-thee-muh-TOH-suhss), known as lupus, worsens. Pregnancy is also known to trigger thyroiditis (theye-roi-DEYE-tiss) after the baby is born. Yet the question about whether female hormones *cause* these diseases is yet to be answered.

**People with a family history.** Heredity plays an important role. Some diseases run in families, such as lupus, multiple sclerosis (MUHL-tip-uhl sklur-OH-suhss), and vitiligo (vit-uhl-EYE-goh). It is also common for different members of one family to have different types of autoimmune diseases.

For instance:

- A woman may have rheumatoid arthritis.
- Her mother may have Hashimoto's (hah-shee-MOH-tohz) disease.
- Her grandmother may have type 1 diabetes.



To understand this family link, experts need to identify the genes that make people more likely to get certain autoimmune diseases. The good news is that some progress has been made, often by studying families with multiple members who have autoimmune diseases. In the past few years, more has been learned about the genetic basis of rheumatoid arthritis, vitiligo, lupus, psoriasis (suh-REYE-uh-suhss), and others.

For more information on genes and genetic counseling, see pages 408 and 409 of the Appendix.

**People who are around certain things in the environment.** Many things may cause or intensify certain diseases:

- The ultraviolet rays in sunlight can make the symptoms of lupus worse.
- Being around industrial solvents may increase the risk of developing scleroderma (sklair-oh-DUR-muh) or lupus.
- Dietary iodine may be responsible for an increase in the number of people who have thyroiditis.
- Research has linked infections caused by a variety of bacteria and viruses that

have been linked to many immune diseases, including multiple sclerosis, type 1 diabetes, rheumatoid arthritis, lupus, and others. Sex hormones may further boost the immune system's overreaction to infections in women who are already at risk for these diseases. This could help explain why these diseases are more common in women.

Although these links have been seen, experts don't yet know if avoiding infections and sunlight can stop an autoimmune disease from happening. And other possible triggers, such as some metals, need to be studied more.

**People with certain ethnic backgrounds.** Experts are not yet sure why, but some ethnic groups seem to be at greater risk of certain diseases.

- Type 1 diabetes is more common in white people.
- Lupus is three times more common in African American women. Lupus is also more common in Hispanic, Asian, and American Indian women. The disease is more severe for African American and Hispanic people, who also develop symptoms at a younger age.

### Common Links Among People With Autoimmune Diseases

- women of childbearing age
- people with a family history
- people who are around certain things in the environment
- people of certain ethnic backgrounds

- Choctaw Native Americans have higher rates of scleroderma. African Americans, Hispanics, and Native Americans may also have more severe forms of the disease.

These differences may be due to a genetic link. Exposure to similar things in the environment may also explain why certain communities are affected more than others.



### Genes + Environment

Inheriting certain genes can raise your risk of getting an autoimmune disease, but it may be an event or exposure to something outside of your body that actually triggers it.

The role of environmental exposures in the absence of a genetic link is still unclear. In the case of heart disease, we know you can lower your risk by eating less saturated fat, exercising, and taking other heart-healthy steps. We don't yet know if the things you do—or don't do—can raise or lower your risk of autoimmune diseases on their own.

### Types of autoimmune diseases

Some autoimmune diseases are life threatening. Nearly all of these diseases are debilitating and require lifelong medical care. Although each is unique, these diseases in general have much in common. Many of them share hallmark symptoms, such as fatigue, dizziness, and low-grade fever. Many also go through remissions, when symptoms go away, and “active” disease stages, when symptoms flare.

The autoimmune diseases discussed in the following chart are more common in women than in men.

Types of Autoimmune Diseases				
Disease	Body part(s) involved	Who gets it?	Symptoms	Tests to find out if you have it (See page 91 for a blood test glossary.)
<p><b>Antiphospholipid antibody syndrome (aPL)</b></p> <p>A disease that causes problems in the inner lining of blood vessels resulting in blood clots in arteries or veins.</p> <p><i>Also called sticky blood syndrome</i></p>	<p>Clots can develop in the brain, the veins of the legs and lungs, or in the placenta of pregnant women.</p>	<p>More common in women</p>	<ul style="list-style-type: none"> <li>• Blood clots in veins or arteries</li> <li>• Multiple miscarriages</li> <li>• Lacy, net-like red rash on the wrists and knees</li> </ul>	<ul style="list-style-type: none"> <li>• Blood test</li> <li>• The disease is suspected if you have a history of blood clots or multiple miscarriages.</li> </ul>

## Types of Autoimmune Diseases

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<p><b>Graves' disease</b></p> <p>A disease that causes the thyroid gland to make too much thyroid hormone.</p> <p><i>Also called diffuse thyrotoxic goiter or overactive thyroid</i></p>	Thyroid gland	Women older than 20, although it may occur at any age and may also affect men	<ul style="list-style-type: none"> <li>• Insomnia (not being able to sleep)</li> <li>• Irritability</li> <li>• Weight loss</li> <li>• Heat sensitivity</li> <li>• Sweating</li> <li>• Fine brittle hair</li> <li>• Muscle weakness</li> <li>• Light menstrual periods</li> <li>• Bulging eyes</li> <li>• Shaky hands</li> </ul> <p>You may have no symptoms.</p>	Blood test for thyroid-stimulating hormone (TSH)
<p><b>Hashimoto's thyroiditis</b></p> <p>Inflammation of the thyroid gland that stops it from making enough thyroid hormones. It is the most common thyroid disease in the United States.</p> <p><i>Also called autoimmune thyroiditis, chronic thyroiditis, or underactive thyroid</i></p>	Thyroid gland	<ul style="list-style-type: none"> <li>• Middle-aged women</li> <li>• People with a family history</li> </ul>	<ul style="list-style-type: none"> <li>• Fatigue</li> <li>• Weakness</li> <li>• Weight gain</li> <li>• Sensitivity to cold</li> <li>• Muscle aches and stiff joints</li> <li>• Facial swelling</li> <li>• Constipation</li> </ul>	Blood test for thyroid-stimulating hormone (TSH)
<p><b>Multiple sclerosis</b></p> <p>A disease in which the immune system attacks the protective coating, called myelin, around the nerves. The damage affects the brain and spinal cord, causing muscle weakness, loss of coordination, and vision and speech problems.</p>	Central nervous system (brain and spinal cord)	<ul style="list-style-type: none"> <li>• More common in women than men</li> <li>• Most common between ages 20 and 40, but can strike at any age</li> </ul>	<ul style="list-style-type: none"> <li>• Weakness and trouble with coordination, balance, seeing, speaking, and walking</li> <li>• Paralysis</li> <li>• Tremors</li> <li>• Numbness and a tingling feeling in the arms, legs, hands, and feet</li> <li>• Symptoms vary because the location and extent of each attack vary.</li> </ul>	<ul style="list-style-type: none"> <li>• An exam of your body</li> <li>• An exam of your brain, spinal cord, and nerves (a neurological exam)</li> <li>• X-ray tests</li> <li>• Other tests on the brain and spinal cord fluid</li> </ul>

## Types of Autoimmune Diseases

Disease	Body part(s) involved	Who gets it?	Symptoms	Tests to find out if you have it (See page 91 for a blood test glossary.)
<p><b>Myasthenia gravis (MG)</b> (meye-uhss-THEEN-ee-uh GRAV-uhss)</p> <p>A disease in which the immune system attacks the nerves and muscles, causing weakness and problems with seeing, chewing, walking, and talking.</p>	<p>Muscles throughout the body and the thymus gland, which is in the chest</p>	<ul style="list-style-type: none"> <li>• Can affect people at any age</li> <li>• Most common in young women and older men</li> </ul>	<ul style="list-style-type: none"> <li>• Double vision, trouble keeping a steady gaze, and drooping eyelids</li> <li>• Trouble swallowing, with frequent gagging or choking (called a <i>crisis</i>)</li> <li>• Weakness or paralysis</li> <li>• Muscles that work better after rest</li> <li>• Drooping head</li> <li>• Trouble climbing stairs or lifting things</li> <li>• Trouble talking</li> </ul>	<ul style="list-style-type: none"> <li>• Physical and neurologic exams</li> <li>• Blood test</li> <li>• Injection of a drug that briefly improves muscle strength in people with MG</li> <li>• Nerve stimulation tests that can show impaired nerve-to-muscle communication in people with MG</li> <li>• Tests to measure breathing strength</li> </ul>
<p><b>Rheumatoid arthritis</b></p> <p>A disease in which the immune system attacks the lining of the joints throughout the body.</p>	<p>Joints, lungs, heart, and other organs</p>	<p>Usually occurs in people between ages 25 and 55</p>	<ul style="list-style-type: none"> <li>• Joint pain, stiffness, swelling, and malformation</li> <li>• Reduced movement and function</li> </ul> <p>May have:</p> <ul style="list-style-type: none"> <li>• Fatigue</li> <li>• Fever</li> <li>• Weight loss</li> <li>• Eye inflammation</li> <li>• Anemia (uh-NEE-mee-uh)</li> </ul>	<ul style="list-style-type: none"> <li>• An exam of your body</li> <li>• X-rays of the joints</li> <li>• Blood test to detect anemia, the antibody rheumatoid factor (RF), and citrulline antibodies (CCP). (Some people with RF never get this disease. Others who have this disease do not have this antibody.)</li> <li>• Test of the fluid in the joints may be needed</li> </ul>

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<p><b>Scleroderma</b></p> <p>A disease causing abnormal growth of connective tissue in the skin and blood vessels. In more severe forms, this tissue can build up internally, leading in some cases to organ failure.</p>	<p>Skin and possibly the kidneys, lungs, heart, and gastrointestinal tract</p>	<ul style="list-style-type: none"> <li>• People 30 to 50 years old, more often women</li> <li>• People around silica dust and polyvinyl chloride may be at risk</li> </ul>	<ul style="list-style-type: none"> <li>• Fingers and toes that turn white, red, or blue in response to heat and cold (called Raynaud phenomenon)</li> <li>• Pain, stiffness, and swelling of fingers and joints</li> <li>• Thickening of the skin</li> <li>• Skin that looks shiny on the hands and forearm</li> <li>• Tight and mask-like facial skin</li> <li>• Sores on the fingers or toes</li> <li>• Trouble swallowing</li> <li>• Weight loss</li> <li>• Diarrhea or constipation</li> <li>• Shortness of breath</li> </ul>	<ul style="list-style-type: none"> <li>• Exam of the skin for tightness, thickening, and hardening</li> <li>• Blood tests</li> <li>• Urine test</li> <li>• Chest x-ray</li> <li>• Lung function test</li> <li>• Skin biopsy</li> </ul>
<p><b>Sjögren's syndrome</b> (SHOH-grins)</p> <p>A disease in which the immune system targets the glands that make moisture, such as tears and saliva, leading to dryness of the eyes, mouth, and other body tissues.</p>	<p>Mucous membranes, such as the eyes and mouth</p>	<p>Most common in women 40 to 50 years old</p>	<ul style="list-style-type: none"> <li>• Dry eyes or eyes that itch</li> <li>• Dryness of the mouth, which can cause sores</li> <li>• Trouble swallowing</li> <li>• Loss of sense of taste</li> <li>• Severe dental cavities</li> <li>• Hoarseness</li> <li>• Fatigue</li> <li>• Joint swelling or pain</li> <li>• Swollen glands</li> <li>• Cloudy eyes</li> </ul>	<ul style="list-style-type: none"> <li>• Blood tests</li> <li>• Biopsy of the salivary gland</li> <li>• A test to see if you make enough tears</li> <li>• An eye test using a special dye</li> </ul>

## Types of Autoimmune Diseases

Disease	Body part(s) involved	Who gets it?	Symptoms	Tests to find out if you have it (See page 91 for a blood test glossary.)
<p><b>Systemic lupus erythematosus</b></p> <p>A disease that can damage the joints, skin, kidneys, and other parts of the body.</p> <p><i>Also called SLE or lupus</i></p>	<p>Skin, joints, lungs, kidneys, brain, lungs, and heart</p>	<p>Mostly young women</p>	<ul style="list-style-type: none"> <li>• Fever</li> <li>• Weight loss</li> <li>• Hair loss</li> <li>• Mouth ulcers (sores)</li> <li>• Extreme fatigue</li> <li>• “Butterfly” rash across the nose and cheeks</li> <li>• Rashes on other parts of the body</li> <li>• Painful or swollen joints and muscle pain</li> <li>• Sensitivity to the sun</li> </ul>	<ul style="list-style-type: none"> <li>• An exam of your body</li> <li>• Urine test</li> <li>• Blood test</li> </ul>

Other autoimmune diseases include Addison’s disease, vitiligo, type 1 diabetes, and celiac (SEE-lee-ak) disease. You are more likely to get a second autoimmune disease if you already have one. For instance, people with Addison’s disease often have type 1 diabetes.

### Getting diagnosed

You may not have a clear pattern of symptoms at first. You may not have the same pain or problem every time. Some diseases may also not have any symptoms until they have advanced. And most of

these diseases lack the diagnostic “checklist” that helps doctors identify them early. Many tests and exams may be needed to make a diagnosis.

The following steps will help your doctor diagnose your disease:

- **Medical history.** The doctor will ask about your symptoms and how long you have had them. Your symptoms may not point to one disease. But they can be a starting point for your doctor. Tell your doctor if you have a family member with autoimmune disease.
- **Physical exam.** Your doctor will check for signs such as swollen joints or lymph nodes, or skin that looks off color.
- **Medical tests.** No one test will show that you have an autoimmune disease. But doctors may find clues in a blood sample. (See page 91 for information on blood tests.)

### Digestive Diseases

There are some autoimmune diseases that affect the digestive system that are more common in women. For more information on Crohn’s disease, autoimmune hepatitis, primary biliary cirrhosis (BIL-ee-air-ee sur-ROH-suhss), and ulcerative colitis, see the *Digestive Health* chapter on page 265.

## What type of blood tests may be done?

### **Antinuclear antibody or ANA (also known as fluorescent antinuclear antibody):**

This test detects autoantibodies. The presence of ANA can be a marker or sign of several autoimmune diseases. ANA is most commonly seen in lupus.

### **Rheumatoid factor (RF):**

This test detects and measures RF, an autoantibody that can mean you have rheumatoid arthritis, Sjögren's syndrome, or other autoimmune diseases. Some people have RF without any disease.

### **C-reactive protein (CRP):**

C-reactive protein is a substance made by the liver that can be found in the blood. A high level of this substance can mean there is inflammation in the body. This test can help diagnose inflammatory bowel disease, rheumatoid arthritis, lupus, and other diseases.

### **Erythrocyte sedimentation rate (ESR):**

This test is used to measure inflammation. It can't tell exactly where the inflammation is, so it is used along with other tests.

### **Citrulline antibody (CCP or anti-CCP):**

This fairly new test detects citrulline antibodies, thought to be made by the immune system during inflammation. CCP can be useful in diagnosing rheumatoid arthritis early, especially in people who have symptoms but do not have RF (see RF test above).

Some people may be able to get a diagnosis quickly. For others, the process is much slower. Some people may be told they have something autoimmune related, but they are unable to get a precise label for their symptoms. Others find they can't get a diagnosis at all and spend years searching for answers. Still others find it difficult to get a *correct* diagnosis. Sadly, many patients have been told that their symptoms were stress related or in their heads. The hope is that increased awareness and research efforts will improve this experience. In the meantime, there are steps you can take to help make things easier.

### **What you can do:**

- Write down your family's health history and share it with your doctor. Include all of the health problems your parents, siblings, grandparents, and cousins (if possible) have had.
- Write down all of the symptoms you have had and share the list with your doctor. Some symptoms may not seem related, but they may be after all. Put the symptoms that bother you the most at the top of your list.
- Seek out referrals to good doctors, starting with a specialist who deals with your most major symptom. Check with family members, friends,

and health care professionals in your community for recommendations.

- Ask about your doctor's experience with autoimmune diseases. The more patients he or she has treated, the better.
- Get a second, third, or fourth opinion if need be. If a doctor doesn't take your symptoms seriously or refers you to a psychologist, find another doctor. You know how you are feeling and you are your own best advocate. Be sure to check on your insurance first to find out if it covers your visits.

### Reproductive health

In the past, women with autoimmune diseases were told not to have children. This advice has changed with better treatments and understanding. Many health risks can be lowered by not getting pregnant during active stages of disease, when symptoms flare. Health risks can also be lowered by taking medicine that your doctor says is safe to take while pregnant. There may still be some risks for both the mother and baby, depending on the disease and how severe it is.

But women with autoimmune diseases can safely have children. And, although symptoms may be worse during pregnancy for some women, others may find that their symptoms improve.

### Before Pregnancy

It is important to talk to your doctor before trying to get pregnant. Along with your regular doctor(s), you may also need care from a maternal-fetal-medicine specialist. This type of doctor cares for women with health problems that may affect pregnancy.



## How Autoimmune Diseases Affect Pregnancy

Disease	What you should know about pregnancy
<b>Antiphospholipid antibody syndrome (aPL)</b>	Pregnancy poses serious risks for both mother and baby. These risks include stroke, blood clots, high blood pressure, and repeated miscarriage. For the baby, there is a risk of stillbirth or fetal death, poor growth in the womb, and preterm birth. Pregnant women with aPL often need more frequent prenatal care visits. It is not clear whether this disease gets worse or better during pregnancy.
<b>Hashimoto's thyroiditis</b>	Also called painless thyroiditis or hypothyroidism, some women get this disease while pregnant. It causes thyroid problems in women after the baby is born. These problems are often not permanent. Many times, women have postpartum depression at the same time.

## How Autoimmune Diseases Affect Pregnancy

Disease	What you should know about pregnancy
<b>Lupus</b>	<p>Pregnant women with lupus must be closely watched to help prevent problems such as preterm birth and stillbirth. Treatment may be needed during pregnancy to control your disease.</p> <p>Symptoms tend to worsen during the second half of pregnancy and after the baby is born. Yet this will not make the outcome of the disease worse for you. A long period of remission before getting pregnant can lower your chances of a flare-up during pregnancy.</p> <p>Rarely, babies born to women with lupus have neonatal lupus. This is not the same thing as lupus in adults. Babies with neonatal lupus can have a rash and, sometimes, a problem with their heartbeat. This problem is treatable. Babies with neonatal lupus have only a small chance of having lupus later in life.</p>
<b>Graves' disease</b>	<p>Also called hyperthyroidism, Graves' disease can lead to preterm birth and low birth weight. Women may be at risk of high blood pressure during pregnancy.</p> <p>Pregnancy does not appear to make the disease worse. Some women may have trouble getting pregnant. Pregnant women must have their thyroid levels watched throughout pregnancy. There are certain drugs that may cause birth defects and should not be used.</p>
<b>Rheumatoid arthritis</b>	<p>Symptoms generally improve during pregnancy, often allowing women to take less medicine. Symptoms usually flare up after the baby is born.</p>
<b>Scleroderma</b>	<p>It may be best to wait to get pregnant for some time after the disease is diagnosed. It is important to talk to a doctor about timing. It is not clear if having this disease makes it harder for women to get pregnant, but some drugs can cause infertility.</p> <p>Pregnant women will need to have their blood pressure watched carefully. Skin problems common to patients with scleroderma do not pose extra problems during pregnancy. The disease may be more active following delivery.</p>
<b>Multiple sclerosis (MS)</b>	<p>Symptoms tend to improve during pregnancy. Pregnancy does not appear to make the disease worse. Women who don't yet know they have MS may be more likely to start having symptoms during pregnancy.</p> <p>Having MS may make it hard for women to carry a pregnancy. Muscle weakness, coordination problems, and fatigue may make falls more likely. If in a wheelchair, women may have more urinary tract infections. Labor may also be more difficult, but there are things doctors can do to help.</p>
<b>Myasthenia gravis (MG)</b>	<p>Symptoms that lead to trouble breathing—a crisis—may happen during pregnancy. For some women, though, the disease may go into remission.</p> <p>There are some risks for pregnant women with MG, such as greater chances of preterm labor. It is also possible that the medicine used to treat MG may cause contractions. MG crises are also more likely to happen during labor.</p> <p>Pregnancy does not make the outcome of the disease worse for women.</p>
<b>Sjögren's syndrome</b>	<p>Many women first get this disease after childbearing age. Pregnancy-related problems tend to be tied to lupus or aPL, which patients with Sjögren's often also have.</p>



Experts have long suspected the hormone estrogen to be a lupus trigger, leading them to warn against the use of birth control pills. Yet research has shown birth control pills to be safe in women with lupus.

## Infertility

Some women with autoimmune diseases may have trouble getting pregnant. There are a few reasons behind this challenge:

- Type 1 diabetes, lupus, and hypothyroidism (Hashimoto's thyroiditis) are linked to a higher risk of early menopause or premature ovarian failure (POF). Women with POF stop menstruating before age 40, lack estrogen, and are infertile.
- Infertility is also caused by autoimmune oophoritis (oo-for-EYE-tuhss). With this disease, the body attacks its own cells that release reproductive hormones. This causes ovarian failure.
- Some treatments may cause infertility. Chemotherapy drugs, used to treat severe cases of lupus, can cause fertility to decline early.

Let your doctor know if you are having trouble getting pregnant. There are tests that can be done to see if your autoim-

mune disease is the root of the problem. Your doctor can also tell you if fertility treatments are an option for you.

## Breastfeeding Safety

After pregnancy, it is important to talk to your doctor about the safety of your medications during breastfeeding.

## Other health issues

Fatigue can be a big problem for people who have autoimmune diseases. And some people may also have chronic fatigue syndrome (CFS) or fibromyalgia (feye-broh-meye-AL-juh) (FM) at the same time. Although these two conditions may share similar symptoms, they are not autoimmune diseases. CFS can cause you to have trouble concentrating, feel weak and very tired, and have muscle pain.

FM causes widespread body pain. People with FM also feel tired and have low energy. FM mainly occurs in women of childbearing age.

For more information on chronic fatigue syndrome and fibromyalgia, see the *Pain* chapter on page 351.

People with some autoimmune diseases can also be at greater risk of atherosclerosis (a-thuh-roh-skluh-ROH-suhss) and osteoporosis (OSS-tee-oh-puh-ROH-suhss). Atherosclerosis is the hardening and narrowing of the arteries. This problem can lead to heart disease. It is not clear why people with autoimmune diseases are at greater risk for this problem. People with osteoporosis have

low bone mass and weak bones. This disease leads to increased risk of fractures of the hip, spine, and wrist. Some treatments taken over time can cause osteoporosis. Routine care can help you spot and manage these health problems.

For more information on atherosclerosis, see the *Heart Disease* chapter on page 15. For more information on osteoporosis, see the *Healthy Aging* chapter on page 221.

### Managing your disease

Having an autoimmune disease can cause debilitating symptoms, loss of organ function, reduced productivity at work, and high medical expenses. At the same time, it does not have to stop you from living your life. For many people, the disease does not define them. Rather, it is yet another challenge they can successfully manage. And there are many ways to cope with the different ways in which these diseases can affect your life.

- **How you look and your self-esteem.** Depending on your disease, you may have discolored or damaged skin or hair loss. Your joints may look different. Such problems can't always be prevented. But their effects can be reduced with treatment. Cosmetics, for example, can hide a skin rash. Surgery can correct a malformed joint.
- **Caring for yourself.** Painful joints or weak muscles can make it hard to do simple tasks. You may have trouble climbing stairs, making your bed, or brushing your hair. If doing daily tasks is hard, talk with a physical therapist. The therapist can teach you exercises

to improve strength and function. An occupational therapist can show you new ways to do things or tools to make tasks easier.

- **Family relationships.** Family members may not understand why you don't have energy to do things you used to do. They may even think you are just being lazy. But they may also be overly concerned and eager to help you. They may not let you do the things you can do. They may even give up their own interests to be with you. Share what you learn about your disease with your family. Involve them in counseling or a support group. It may help them better understand the disease and how they can help.
- **Sexual relations.** Damage to glands that produce moisture can lead to vaginal dryness. This makes intercourse painful. Pain, weakness, or stiff joints may make it hard for you to move the way you once did. You may be unsure of how you look. Or you may be afraid that your partner will no longer find you attractive. With communication, good medical care, and perhaps counseling, many of these issues can be overcome.



## Dealing with doctors

If you have an autoimmune disease, you will likely need to see different health care professionals to treat varied health problems. For instance, patients with lupus may see a rheumatologist to treat the main disease, a nephrologist to treat kidney problems, and a dermatologist for skin problems. This can make getting care tough, especially if insurance coverage is lacking.

It can also be hard if you don't have one doctor in charge of managing your overall care. Without this point person, it may be harder to deal with multiple specialists who don't communicate well with one another. Ask if there is a way to designate one doctor to take the lead. It will also help to partner with your doctors early to learn how to deal with the long-term effects of your disease.

## Treatments

How people fare varies with the specific disease. Most autoimmune diseases are chronic or ongoing, but many can be controlled with treatment. There are many types of treatment available, some of which treat more than one disease. Your treatment depends on the type of disease, how severe it is, and its symptoms. Treatments can do the following:

- **Relieve symptoms.** Relieving symptoms may be as simple as taking a drug for pain relief. It may also be as involved as having surgery.
- **Preserve organ function.** Treatment may be needed to prevent organ damage. Examples include drugs to control an inflamed kidney in people with lupus and insulin injections to regulate



blood sugar in people with diabetes. These treatments don't stop the disease. But they can save organ function. They can also help people live with disease complications.

- **Target disease mechanisms.** Some drugs may also be used to target how the disease works. In other words, they can suppress the immune system. These drugs include chemotherapy, at lower doses than used for treating cancer. A fairly new class of drugs called anti-TNF medications blocks inflammation in people with various forms of autoimmune arthritis and psoriasis. These drugs can lessen pain and improve quality of life for many people.

## Specialists Who Treat Autoimmune Diseases

A **rheumatologist** treats arthritis and other rheumatic diseases, such as scleroderma and lupus.

An **endocrinologist** treats gland and hormone problems, such as diabetes and thyroid disease.

A **neurologist** treats nerve problems, such as multiple sclerosis and myasthenia gravis.

A **hematologist** treats diseases that affect the blood, such as pernicious anemia and autoimmune hemolytic anemia.

A **gastroenterologist** treats problems with the digestive system, such as Crohn's disease and ulcerative colitis.

A **dermatologist** treats problems of the skin, hair, and nails caused by diseases such as psoriasis, lupus, and alopecia areata (AL-uh-PEE-shuh AR-ee-AYT-uh).

A **nephrologist** treats kidney problems, such as inflamed kidneys caused by lupus.

A **physical therapist** helps patients with stiffness, weakness, and restricted body movement with proper levels of physical activity.

An **occupational therapist** helps patients improve their ability to perform daily activities, despite pain or other health problems. Special equipment and devices are used to help make things easier at work and at home.

A **speech therapist** helps people with speech problems from illnesses such as multiple sclerosis.



New treatments may be on the horizon. Experts are studying new drugs that prevent the immune system from attacking healthy body parts. These may prove helpful for treating a number of autoimmune diseases.

### What you can do to feel better

Outside of treatments, there are things you can do to help yourself feel better.

- Eat a healthy diet, including balanced meals.
- Get regular physical activity. But be careful not to overdo it, and talk with your doctor first about physical activity

plans. A gradual and gentle physical activity program often works well for people with long-lasting muscle and joint pain. Some types of yoga or tai chi exercises may also be helpful.

For more information on healthy eating, see the *Nutrition* chapter on page 317. For more information on physical activity, see the *Fitness* chapter on page 337.

- Try to lower your stress. Stress and anxiety can cause symptoms to flare up with some autoimmune diseases. So finding ways to relax can help man-

age a cycle of stress and flare-ups. Try using relaxation techniques, such as meditation. Other coping methods include:

- pacing yourself and your activities
- joining a support group
- talking with a professional counselor

Above all, be patient with yourself. Autoimmune diseases can be a big challenge, but not an impossible one. Care is better today than ever before, and continued improvement is likely. The extensive research taking place holds much promise for better ways to diagnose and treat these diseases. ■

## Watch Your Symptoms

Your doctor may not prescribe a treatment. If your symptoms are mild, the risks of treatment may be worse than the symptoms. But you should watch for signs that your disease is progressing.

- Visit your doctor regularly so that you can catch changes before they lead to serious damage.
- Tell your doctor if your symptoms are flaring up.
- Talk to your doctor before starting any alternative treatments, such as natural supplements.

# One Woman's Story

**A**s a 55-year-old female with diagnosed lupus since 1990, I have many stories to tell: the difficulty in obtaining a diagnosis, the problem with having good treatment options, the anxiety of introducing the disease to both my professional and social communities. I wondered if this disease would change my life goals.

There is also the problem of carrying a disease that does not provide real clues to those who witness the struggle. No one sees the fatigue, the joint pain, the internal damage. Therefore, you can't be too sick. The other side of the coin is that I didn't want to be known as the women *with* lupus. I wanted to be known as the incredible woman with loads of positive characteristics and personality who *has* lupus!

Thankfully, I have found support in many ways and realized the importance of women in women's lives. There are the wonderful women friends who attempt to understand and commit to befriending the disease as well as the person. I have also been fortunate to find a female nurse practitioner who researches and studies ways to assist in dealing with the disease and its challenges.

And support groups are so important—not only for those who confront medical challenges, but because the support of each other as human beings allows us to feel loved, accepted, supported, and respected.

An autoimmune disease can forever alter your self-image, the path you walk, and the journey you have painted for yourself. Once the diagnosis is made, the challenges accepted, and the choices identified, you can repaint your journey. Be an artist who accepts the challenge and is determined to continue the adventure, despite the bumps and curves in the path!

Linda

**Cody, Wyoming**

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**No one sees the  
fatigue, the joint  
pain, the internal  
damage.**

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## For More Information...

### **Office on Women's Health, HHS**

200 Independence Ave SW, Room 712E  
Washington, DC 20201

Web site: [www.womenshealth.gov/faq/  
autoimmune.htm](http://www.womenshealth.gov/faq/autoimmune.htm)

Phone number: (800) 994-9662,  
(888) 220-5446 TDD

### **National Institute of Allergy and Infectious Diseases, NIH**

6610 Rockledge Dr, MSC 6612  
Bethesda, MD 20892-6612

Web site: [www.niaid.nih.gov](http://www.niaid.nih.gov)

Phone number: (866) 284-4107,  
(800) 877-8339 TDD

### **National Institute of Arthritis and Musculoskeletal and Skin Diseases Information Clearinghouse, NIH**

1 AMS Circle

Bethesda, MD 20892-3675

Web site: [www.niams.nih.gov](http://www.niams.nih.gov)

Phone number: (877) 226-4267,  
(301) 565-2966 TTY

### **National Institute of Neurological Disorders and Stroke, NIH**

PO Box 5801

Bethesda, MD 20824

Web site: [www.ninds.nih.gov](http://www.ninds.nih.gov)

Phone number: (800) 352-9424,  
(301) 468-5981 TTY

### **American Autoimmune Related Diseases Association**

22100 Gratiot Ave

East Detroit, MI 48021-2227

Web site: [www.aarda.org](http://www.aarda.org)

Phone number: (800) 598-4668 Literature requests, (586) 776-3900 Patient information

### **American College of Rheumatology**

1800 Century Pl, Suite 250

Atlanta, GA 30345-4300

Web site: [www.rheumatology.org](http://www.rheumatology.org)

Phone number: (404) 633-3777

### **American Thyroid Association**

6066 Leesburg Pike, Suite 550

Falls Church, VA 22041

Web site: [www.thyroid.org](http://www.thyroid.org)

Phone number: (800) 849-7643

### **APS Foundation of America**

PO Box 801

LaCrosse, WI 54602-0801

Web site: [www.apsfa.org](http://www.apsfa.org)

### **Arthritis Foundation**

PO Box 7669

Atlanta, GA 30357-0669

Web site: [www.arthritis.org](http://www.arthritis.org)

Phone number: (800) 283-7800

### **Lupus Foundation of America**

2000 L St NW, Suite 710

Washington, DC 20036

Web site: [www.lupus.org](http://www.lupus.org)

Phone number: (800) 558-0121

Information request line

### **Myasthenia Gravis Foundation of America**

1821 University Ave W, Suite S256

St. Paul, MN 55104

Web site: [www.myasthenia.org](http://www.myasthenia.org)

Phone number: (800) 541-5454

### **National Graves' Disease Foundation**

PO Box 1969

Brevard, NC 28712

Web site: [www.ngdf.org](http://www.ngdf.org)

Phone number: (877) 643-3123

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## For More Information...

### **National Multiple Sclerosis Society**

733 Third Ave

New York, NY 10017-3288

Web site: [www.nationalmssociety.org](http://www.nationalmssociety.org)

Phone number: (800) 344-4867

### **Sjögren's Syndrome Foundation**

6707 Democracy Blvd, Suite 325

Bethesda, MD 20817

Web site: [www.sjogrens.org](http://www.sjogrens.org)

Phone number: (800) 475-6473

### **Scleroderma Foundation**

300 Rosewood Dr, Suite 105

Danvers, MA 01923

Web site: [www.scleroderma.org](http://www.scleroderma.org)

Phone number: (800) 722-4673

