

# What doctors want patients to know about lupus

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Lupus is a chronic autoimmune disease that can affect the skin, joints and vital organs, often with symptoms that come and go. Known as systemic lupus erythematosus, the condition occurs when the immune system attacks healthy tissue. Because lupus can be difficult to diagnose and varies widely from person to person, early recognition and ongoing care are vital to help manage symptoms and reduce complications.

About 1.5 million people in the U.S. have a form of lupus and 90% of people living with lupus are women. Meanwhile, lupus is more prevalent among people who are Black, Hispanic, Native American, Asian and Alaska Native than in white populations. In fact, women who are Black, Native American or Alaska Native are two to three times more likely than white women to develop lupus. They also tend to have more severe cases of lupus.

The AMA's What Doctors Want Patients to Know™ series gives physicians a platform to share what they want patients to understand about today's healthcare headlines.

In this installment, [Brittany A. Bettendorf, MD](#), a rheumatologist with University of Iowa Health Care, took time to discuss what to know about lupus.

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## Lupus is an autoimmune disease

“That means that the immune system is sensitized to recognize and attack the self,” said Dr. Bettendorf. “We all have cells that are recognized and sensitized to attack ourselves, but we have ways that the body cleanses those cells and gets rid of those self-recognizing cells.”

“In lupus, those mechanisms become dysregulated and we have more of those self-recognizing cells that act like soldiers and attack our own body instead of the pathogens that are intruding on our body,” she explained, noting “it’s one of those unique diseases that can involve many different organ systems.”

“For some of my patients, lupus is very mild and has little impact on their day to day, but in many patients, it can be very severe or even life-threatening,” Dr. Bettendorf said.

## Symptoms of lupus depend on organs affected

“Which symptoms a person experiences depends on which organs systems their lupus affects,” Dr. Bettendorf said, noting that “patients with lupus experience different combinations and severity of symptoms.”

The most common symptoms of lupus often include:

- Pain in your joints, muscles or chest.
- Joint swelling or arthritis.
- Rashes, such as a butterfly rash across your face, often sensitive to sunlight.
- Kidney problems.
- Headaches.
- Fever.
- Hair loss.
- Mouth sores.
- Fatigue.
- Shortness of breath.
- Swollen glands.
- Changes in mood or brain fog.
- Blood clots.

“Patients typically experience symptoms in waves, referred to as flare-ups, which can affect their daily routine,” she said, noting that “your physician can help manage flare-ups and prevent them.”

## There are four different types of lupus

“Lupus has four broad categories or different types,” said Dr. Bettendorf. “Although, lupus actually has many subtypes within those categories.”

“**Systemic lupus erythematosus, or SLE**, is the most common type,” she said, noting that “typically, when we talk about lupus, we’re talking about systemic lupus.”

**Cutaneous lupus erythematosus** is another type, “which refers to a form of lupus that is typically restricted to the skin and doesn’t involve other internal organs,” Dr. Bettendorf said, noting there are different subtypes of cutaneous lupus, “such as chronic cutaneous lupus, which is also called discoid lupus, and can be very challenging to manage, can be difficult to get to respond to medications, can have a big impact on patients’ lives and can be disfiguring.”

Acute cutaneous lupus is another subtype and “manifests as the butterfly rash that’s across the cheek area,” she said. “That butterfly rash is often associated with the systemic form of lupus but doesn’t scar and can go away when lupus is more controlled.”

**Medication-induced lupus** is another type. “This can be caused by medication or something that we’re ingesting. It could even be caused by herbal supplements,” Dr. Bettendorf said. “This exposure then triggers an autoimmune reaction in the body that looks like a systemic lupus but is actually triggered by a medication. If that medication is determined and withdrawn, that person will often get better simply by stopping the use of that medicine.”

**Neonatal lupus** is the fourth form, which is a very different condition than the other types. “It happens in an infant and is related to transplacental passage of specific antibodies from mother to child which occur during pregnancy. These are antibodies from the mother that are seen in a condition called Sjögren’s disease. These antibodies cross the placenta over

to the baby and can lead to the development of neonatal lupus,” she said. “Usually within six to eight months—as soon as the mom’s antibodies get out of the system—those symptoms clear and the condition self resolves.

“In rare cases, this condition can cause heart blockage, leading to a scar in the baby’s electrical conduction system in the heart. When that happens, it can lead to permanent damage and the baby may require a pacemaker. Fortunately, that is quite rare,” Dr. Bettendorf added.

## **Lupus flare-ups come and go**

With lupus, symptoms typically come and go in waves called flare-ups. During a flare-up, a person’s symptoms may be severe enough that it can affect their daily routine. However, in between flare ups, there may be periods of time where there are no symptoms, or they are mild. When this happens, it is called being in remission.

Additionally, lupus symptoms often develop slowly with many noticing one or two signs at first. Then, a person might experience more or different symptoms later on as the condition is established.

## **The cause of lupus is unknown**

“We don’t really know the cause of lupus,” Dr. Bettendorf said, noting that “there’s no single gene for lupus that’s been identified. In fact, there’s probably over 100 different genetic risks or changes that have been associated with lupus.”

“The tricky part is it depends on other factors too. But if someone has a strong genetic predisposition for their disease, it might not take as significant of an environmental exposure to get the disease,” she said. “Whereas somebody with a weaker genetic predisposition might need more environmental factors to develop the disease. So, we think there’s a combination of genetic factors, environmental triggers, hormonal risks, and immune system dysfunction that all contribute to development of lupus.

“One environmental trigger that could lead to development of lupus is UV light exposure. And, in an individual who already has lupus, when they do get exposed to sunlight, it can cause flares too,” Dr. Bettendorf said, adding that your health history plays a role too. Smoking, experiencing a lot of stress and having certain other health conditions may also trigger lupus.

## **Lupus can affect nearly any organ system**

“Because lupus is a multisystem disorder, it can affect nearly any organ system in the body, so complications are going to depend on which organs are involved,” Dr. Bettendorf said. “For example, if the heart is involved, one could have heart disease, heart failure, fluid around the heart, or electrical conduction abnormalities in the heart.”

Similarly, “if the lungs are involved, one might develop fluid around the lungs, irritation of the lining of the lungs, or shortness of breath as a complication,” she said. “Kidney disease is at the forefront because we think about a condition called lupus nephritis, which means that lupus has attacked the kidney tissue. Lupus nephritis happens in about 40%–50% of people with lupus.”

“Another complication of lupus is related to our treatments for the disease, which pose an infection risk because we manage autoimmune disease with immunosuppression,” Dr. Bettendorf said. “When we stamp down the immune system, we stamp down that self-reactivity, but we also stamp down its reactivity to other things that we want it to be reactive to like infections.”

Additionally, “you can have neurologic complications of lupus such as stroke or seizure which are less common. The most common neurologic or psychiatric manifestations are cognitive dysfunction, often referred to as brain fog, and depression,” she said. “Having lupus can also increase the risk of pregnancy-related complications such as miscarriage, preterm birth, or pre-eclampsia.”

## **There are risk factors for lupus**

“When we think about risk factors, we think about those which are modifiable—that is, things we can change and adjust in our lives to try to help prevent lupus—and then we have our nonmodifiable risk factors, which is what we were given at birth and we can’t change,” Dr. Bettendorf said. For example, “our genetic predisposition, we can’t change. If you were born into a family where there are family members with lupus or other autoimmune conditions, that’s going to be a risk factor that you carry.”

“Other nonmodifiable risk factors would be being chromosomally female, which is a risk for developing lupus because we know the condition is a lot more common in female patients,” she said. “We also can’t change our age. Lupus most commonly develops in people 15 to 45 years old.”

“Race and ethnicity are also something that is nonmodifiable, but can pose risk factors for lupus,” Dr. Bettendorf said, noting “we do see the condition more commonly in our Black, Hispanic, Asian, Native American and Alaska Native populations.”

“Modifiable risk factors include living a healthy lifestyle, particularly avoiding smoking and tobacco products, reducing exposure to stress, protecting yourself when exposed to the sun, avoiding exposure to toxins and certain medications, and getting adequate sleep,” she said.

## **Lupus requires a clinical diagnosis**

“It’s important to know that lupus is a clinical diagnosis. What I mean by that is there’s no one test that is going to say someone has lupus,” Dr. Bettendorf said. “In fact, lupus cannot be diagnosed by a blood test and shouldn’t be.”

“We have laboratory criteria and clinical criteria and people need a combination of both to be diagnosed with lupus,” she said, noting that while we do use blood tests and other testing, “I would never diagnose someone with lupus based on blood work alone.”

“The ANA test, or antinuclear antibody test is a screening test for lupus. But the ANA test is positive in about 20% of healthy people walking around,” Dr. Bettendorf said. “If we were to check the ANA, one in every five people are going to be positive. The ANA is a broad

screening test and only a small proportion of people with a positive ANA will have lupus.”

“Because it is so common to have a positive ANA, it’s the No. 1 reason that patients get referred to rheumatology and most of the time the ANA is not clinically meaningful, but people come in really scared that they have lupus,” she said. “Other things that we would look at would be blood counts because people with lupus can get low hemoglobin, which we call anemia. They can have low white blood cell counts, which are the cells that fight infections. And they can have low platelets, which are the cells that help to form clots.”

“We often do see changes in blood counts in people with lupus. We also look at kidney function, which can become affected. We look at the urine for blood and protein,” Dr. Bettendorf said, noting that “we would look at all of those things and then we use a point system criteria that we add up to help us make the diagnosis.”

## **Hydroxychloroquine is a key treatment for lupus**

“The most important medical treatment out there for lupus is hydroxychloroquine,” said Dr. Bettendorf. “There are lifestyle changes too that are really important, but the most important medication is hydroxychloroquine.”

“Everybody with lupus should be using hydroxychloroquine unless there’s a contraindication. If they’re allergic to it or they’ve had a problem related to it in the past, then they shouldn’t be on it,” she said. “But otherwise, every patient with lupus should be on it.”

“This medication has been shown to help patients live longer when they have lupus. It helps prevent flares, worsened organ involvement, and it is thought to help prevent transplacental passage of Sjögren’s disease antibodies to the infant in people who are of childbearing age, thus having a preventative role against neonatal lupus,” Dr. Bettendorf said. “People enjoy more life years, they have less flares and less organ damage, so it’s a really important medicine.”

“Other treatments depend on the organ involved and the severity of the disease. We have a lot of disease modifying anti-rheumatic drugs, or what we call DMARDs, that we use in a

lot of different diseases, including lupus,” she said. “And we have biologic medications that we also use in lupus. It really depends on what organ systems are involved and how sick the patient is to help figure out the right combination of treatment options that we should be using to control their condition.”

## **Quitting smoking is key**

“I always tell patients who smoke that quitting smoking is the single best thing you can do for your health because it affects your body in so many different ways,” Dr. Bettendorf said. “Never smoking—or quitting smoking—is really important in preventing many diseases.”

“An important modifiable risk factor for development of lupus is not smoking or quitting smoking,” she emphasized.

## **Take steps to prevent infections**

“Infections are another important cause of increased morbidity and mortality in patients with lupus,” Dr. Bettendorf said, explaining that “we may not be able to control what we’re exposed to, but we can control things like good handwashing and avoiding others who are known to be ill with something contagious,” she said.

## **Protect yourself when out in the sun**

“Sun exposure is probably the biggest environmental risk for lupus flare-ups beyond smoking. That is why staying out of the sun is really important for patients with lupus,” Dr. Bettendorf said. “If you love the sun and want to go out in the sun, then there are certain times of the day that are a little safer to go out in the sun.”

“In the morning or in the later afternoon are going to be better than when the sun is blaring down on us in the heat of the day,” she said. “But if you want to go out in the sun, you need a wide brimmed hat, UV protective clothing that ideally covers most of your skin and wear sunscreen on your body.”

## Lupus is a lifelong condition

“There is no cure for lupus, but we can help people to live longer and healthier lives with the medications, treatments and good lifestyle modifications that we recommend,” Dr. Bettendorf said. “It’s not a death sentence by any means. It just means that the patient is going to have a long and fruitful relationship with their rheumatologist and primary care doctor for their lupus management.”

“They may also need a multidisciplinary care team if other organs become involved. For example, they might need a cardiologist for their heart or a nephrologist for their kidney or other specialists as needed,” she said. “It might be once a month. It might be every three months or every six months, but this will be part of their life moving forward to help keep them healthy.”

Additionally, patients with lupus “might have lower energy levels or there might be times when they just don’t feel as good if the condition is flaring, but those are things that we can help with,” Dr. Bettendorf said. “It is important for people with lupus to come and see us and share how they’re feeling so that we can help.”