

LUPUS In the Veteran Community

What is lupus?

Lupus is a chronic (long-lasting) autoimmune disease in which the immune system, for unknown reasons, becomes over-active and attacks normal healthy cells and tissues. This attack results in inflammation and brings about symptoms. Lupus is one of many autoimmune diseases, where immune activity is directed against the self ("auto").

Is there a test to diagnose lupus?

There is not just one "lupus test," but there is a screening test called the ANA or anti-nuclear antibody test that is positive in almost all cases of lupus. It is not a test typically run as part of military physicals, so it must be on the doctor's radar to be ordered. If the test comes back negative, it is very unlikely you have lupus. If the test is positive, there are a number of diseases that can cause a positive ANA, as well as 10-20% of healthy individuals can have borderline positive testing. There are a couple of other blood tests that are relatively specific for lupus, but positivity in these tests does not make the diagnosis of lupus. The lab tests help confirm the doctor's diagnosis, which is made on the symptoms and physical exam of the patient.

Can you have lupus with negative lab tests?

The ANA (anti-nuclear antibody) test is positive in almost all lupus patients (95-98%) and in studies of military personnel who eventually developed lupus, this antibody was detected in their blood many years before the disease onset or diagnosis. So the chances are pretty small of having systemic lupus if you are ANA negative (but it's possible). On the flip side, many people who do not have lupus (particularly family members of patients) can have a positive ANA test and never develop the disease. Many of the other tests/antibodies are only positive in subsets of patients, so they are helpful, but not necessary for the diagnosis. For example, the anti-dsDNA antibody test is found in about 60% of patients with systemic lupus and the anti-Smith antibody test is found in only 30% of patients.

What is inflammation?

Literally it means setting on fire. It is a protective process our body uses when tissues are injured. Inflammation helps to eliminate a foreign body or organism (virus, bacteria) and prevent further injury. Signs of inflammation include; swelling, redness, pain and warmth. If the signs of inflammation are long lasting, as they can be in lupus, then damage to the tissues can occur and normal function is impaired. This is why the treatment of lupus is aimed at reducing the inflammation.

Who gets lupus?

Military personnel are at potentially high risk of lupus, given their exposure to high stress and environmental contaminants — the combination of which may contribute to immune system dysfunction. Lupus can occur at any age and in either sex, but the highest risk is during late-adolescence/young-adulthood. Nine out of ten people with lupus are women. During the childbearing years (ages 15-44) lupus strikes women 10-15 times more frequently than men. People of all races can have lupus. However, African-American women have a three times higher incidence (number of new cases) and mortality than

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Caucasian women. They tend to develop the disease at a younger age and to develop more serious complications. Lupus is also more common in women of Hispanic, Asian, and Native American descent.

Are there different kinds of lupus?

The most common forms of lupus diagnosed in military personnel and veterans include cutaneous lupus and systemic lupus erythematosus. The four main forms of lupus include:

1. Cutaneous lupus erythematosus affects the skin. There are many different types of cutaneous lupus including:
 - Chronic cutaneous LE (CCLE), which is sometimes called discoid;
 - Subacute cutaneous LE (SCLE); and
 - Acute cutaneous LE (ACLE).
2. Systemic lupus erythematosus (SLE) attacks multiple systems in the body, which may include: the skin, joints, lungs, blood, blood vessels, heart, kidneys, liver, brain and the nervous system.
3. Drug-induced lupus may develop after taking certain prescription medications. Symptoms generally disappear within weeks to months after the drug is discontinued.
4. Neonatal lupus, a fourth type, is a rare condition. It is not the same thing as SLE.

What are the symptoms of lupus?

Initial lupus symptoms often include fatigue, weight loss, joint pain and “flu like symptoms,” which could initially be attributed to the activities and stressors of military service. Symptoms of lupus vary widely depending on the individual case and the form of lupus present. Most people with lupus do not experience all of these symptoms. The list only serves to alert people to clues that might indicate the presence of lupus in an undiagnosed person.

- Achy or swollen joints
- Persistent fever over 100 degrees
- Prolonged, extreme fatigue
- Skin rashes, including a butterfly shaped rash across the cheeks and nose
- Pain in the chest on deep breathing
- Anemia
- Excessive protein in the urine
- Sensitivity to sun or ultraviolet light

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- Hair loss with bald patches
- Abnormal blood clotting problems
- Fingers turning white and/or blue in the cold
- Seizures
- Mouth or nose ulcers lasting longer than two weeks

What do lupus rashes look like?

There is a large variety of ways that lupus rashes can appear. The distinctive rash is called the "butterfly rash," which is a rash that extends across the cheeks of the face and the bridge of the nose. It can be flat or raised; it can be bright red or it can be just a mild blushing, light pink coloration to the skin. It appears on the face in a pattern that looks like a butterfly; the wings are beneath both eyes and the body of the butterfly covers the bridge of the nose.

Another classic rash found in cutaneous lupus is the discoid rash. This rash is coin-shaped or oval in shape, like a disk and it is seen on areas of the skin that are exposed to sunlight. Discoid lesions (sores) tend to be red and raised and become scaly. When they heal they can leave behind a scar. These rashes can also result in a change in coloring of the skin, making the area around the lesion either lighter or darker in color. These discoid lesions may appear on the scalp; on the face in a butterfly distribution; or, as mentioned earlier, in areas where the skin receives sun exposure, especially, for example, the V of the neck.

Can lupus go into remission?

Lupus rarely goes into complete remission where the patient has no symptoms and is on no medication. Most patients can get to a point where their lupus is well controlled with medication but the disease is still there.

Does lupus worsen with age?

Lupus does not really worsen with age per se, but the longer you have it, the more flares will have occurred that can result in further problems with the kidneys or the heart. Patients that develop lupus later in life usually have milder disease than those developing it in their teens or twenties. The average age of military recruits is at the peak time of lupus risk.

What can cause a lupus flare?

Known triggers of a disease flare include exposures that are common among active military and veterans:

- Ultra-violet (UV) light
- Infection

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- Certain antibiotics (for those already diagnosed with lupus, ~25% will experience increased disease activity if they take a sulfa antibiotic)
- Hormones (for example, estrogen-containing birth control pills)
- It is likely that extreme stress may also play a role in triggering lupus flares

What do I need to know about vaccinations if I have lupus?

- Most vaccinations are safe, even for patients with lupus on immunosuppressive medications, but there are certain vaccines required for military personnel traveling to certain areas of the world that need special consideration if you have lupus.
- The CDC recommends you **SHOULD** take:
 - Everybody, particularly pregnant women, the elderly, and immunosuppressed patients like those with SLE should get the yearly influenza (flu) vaccine.
 - Lupus patients should not take the nasal spray version however, because it is “live” vaccine. They must receive the injectable form (which has no active virus components).
 - Pneumococcal vaccine (Pneumovax)
- Vaccines you **MAY** take and are a good idea for many people at risk of exposure:
 - Varicella Zoster vaccine (Zostavax, for shingles) **ONLY IF**:
 - you are on prednisone 20mg daily or less
 - you are on methotrexate 20-25mg or less
 - you are on azathioprine (Imuran) 200mg daily or less
 - you are **NOT** on any biologic medications (ex. Rituxan or Benlysta)
 - DTaP – diphtheria/tetanus/pertussis
 - Hepatitis B vaccine series
 - HPV – papilloma virus
- Vaccines you **SHOULD NOT** take (LIVE vaccines) if you are on immunosuppressant medication for lupus due to the risk of developing the infection:
 - Intranasal Flu vaccine
 - MMR – mumps/measles/rubella
 - Typhoid

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- Adenovirus
 - Rotavirus
 - Small pox
 - Yellow Fever
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- NOTE that hydroxychloroquine (Plaquenil) is a medication for lupus, but is not considered an immunosuppressant. It modulates the immune system without making you more prone to infections. So hydroxychloroquine is safe to be taking while getting live vaccines.

Is lupus a fatal disease?

Lupus is not a universally fatal disease. In fact, today with close follow-up and treatment, 80-90% of the people with lupus can expect to live a normal life span. Lupus does vary in intensity and degree, however, and there are people who have a mild case, there are those who have a moderate case and there are some who have a severe case of lupus, which tends to be more difficult to treat and bring under control. For people who have a severe flare-up, there is a greater chance that their lupus may be life-threatening. We know that some people do die of this disease and because of that we have a tremendous amount of respect for the potential of this disease. However, the majority of people living with lupus today can expect to live a normal lifespan.

When people “die of lupus”, what does that mean?

Overwhelming infection and kidney failure are the two most common causes of death in people with lupus.

If I've been diagnosed with lupus, what can I do to prevent a lupus flare up?

- Limit direct sunlight exposure and wear sunblock daily.
- Go see your doctor regularly for checkups.
- Take your prescribed medications.
- Reduce your risk of infections (with hand washing and immunizations, for example).
- Don't smoke.
- Take good care of yourself - Eat a balanced diet, exercise regularly, get plenty of rest and make sure you get adequate good quality sleep.
- Sometimes lupus will flare even when you are doing “all of the right things” – that is the unpredictable nature of lupus and why the ongoing research being done to better understand and treat lupus is so important.