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Tip Sheet: Lupus

What is the problem?

Lupus is an unpredictable and misunderstood autoimmune disease that can affect the body's joints and any organ, including the skin, kidneys, brain, heart and lungs. It causes the immune system to see the body's healthy cells as foreign invaders and attacks them.

No two cases of lupus are exactly alike. Its health effects can range from a skin rash to a heart attack to kidney failure. It strikes without warning, has unpredictable and sometimes fatal effects, lasts a lifetime, and has no known cause and no known cure.

According to 2005 CDC publication estimates, at least 322,000 people have definite or probable lupus. Women of color have shown to be at a disproportionately high-risk for developing lupus. Many scientists believe that lupus develops in response to a combination of factors both inside and outside the body, including hormones, genetics and environment. There is also no single test to diagnose lupus. On average, it takes years for people with lupus to be diagnosed from the time they first notice their symptoms.

Early diagnosis is critical to managing symptoms and preventing long-term health consequences of the disease. More research is also needed to develop safer and more effective treatment options. Only one drug has ever been developed specifically to treat lupus and approved by the U.S. Food and Drug Administration. Medications used to treat lupus can have very serious side effects, leading to increased risk of infection, cancers, bone loss, diabetes and infertility.

Symptoms of Lupus

Symptoms of lupus come and go, change over time, and often imitate other illnesses, making lupus difficult to diagnose.

- Skin Rashes
 - a red “malar” rash or color change that may appear across the cheeks and bridge of the nose in the shape of a butterfly. Rashes could also occur on the ears, upper arms, shoulders, chest and hands.

- Overwhelming fatigue no matter how much sleep you get, so the disease looks invisible to family, friends and co-workers
- Joint swelling and pain
 - Pain that makes simple tasks like raising your arm to brush hair or tying your shoes impossible.
- Low-grade fevers that last for days or weeks and can't be explained
- Skin lesions that appear or worsen with sun exposure (photosensitivity)
- Shortness of breath
- Headaches, confusion and memory loss
- Pain in your chest when you take a deep breath
- Re-occurring sores in your mouth
- Fingers turning white and/or blue when cold (Raynaud's phenomenon)

Who does it affect?

- While lupus can strike anyone at any time, 90 percent of the people living with lupus are females.
- Lupus strikes mostly women of childbearing age, between the ages of 15-44, often affecting their ability to have a career or children.
- Women of color are at 2-3 times greater risk for lupus. A 2014 CDC-funded study found that minority women tend to develop lupus at a younger age, experience more serious complications and have higher mortality rates.

Living with lupus and managing symptoms

The severity of lupus can range from mild to life threatening. The potential complications of lupus can include:

- Heart attacks
- Strokes
- Seizures
- Infertility or high-risk pregnancy
- Neurological inflammation and dysfunction
- Pericarditis (inflammation of the lungs and heart)
- Kidney complications, potentially resulting in kidney failure

While lupus can be disabling and fatal, the disease can be managed in most cases through aggressive medical treatment and lifestyle changes. Since there is no cure for lupus, the goal of treatment is to manage symptoms and minimize damage to organs. The approach to treatment depends on the type and the severity of disease, general health and lifestyle.

General recommendations for all patients include sun protection, proper diet and nutrition, exercise, no smoking, management of comorbid conditions and taking precautions to prevent

infection. The unpredictability of the disease makes it difficult to manage. The financial, emotional and physical toll of lupus is significant.

- People with lupus surveyed take nearly eight prescription medications to manage all their medical conditions
- 84 percent of people with lupus surveyed indicate they feel they are a burden to their family and friends due to their inability to perform daily activities. In addition, 94 percent indicate that lupus interferes with their ability to enjoy life.
- More than half (55 percent) of people with lupus surveyed whose work is affected are working part-time, intermittently or are unemployed because of lupus.
- A 2008 study published in *Arthritis & Rheumatology* found that the average annual direct health care costs of patients with lupus was \$12,643.

The Bottom Line:

Lupus continues to present many unanswered questions, and getting a diagnosis can take years. It affects all areas of an individual's life, emotionally, financially and physically. A good doctor-patient relationship and support from family and friends can help people with lupus cope with this chronic and often unpredictable illness.

Public awareness of lupus remains low—73 percent of Americans between the ages 18-34 have either not heard about lupus or know little or nothing about lupus beyond the name. This is particularly disturbing because this is the age group at greatest risk for the disease.

Increased public understanding of the signs and symptoms of lupus and its challenges are critical to getting people diagnosed and treated sooner.

CDC funds organizations like the Lupus Foundation of America and American College of Rheumatology to conduct activities to increase the knowledge and awareness of the signs, reduce the time to diagnosis and improve patient self-management practices. More information about CDC and its partners' lupus efforts is available at: www.cdc.gov/lupus.

Case Example:

[Wendy Rodgers](#) is a native Texan and science teacher in Southern California who was diagnosed with lupus at age 27. Her journey with the disease started when she woke up one day unable to move. She was diagnosed after the doctors discovered that lupus had affected her kidneys so badly that she was immediately admitted to the hospital. Shortly after, she experienced an avalanche of complications, including grand mal seizures, brain inflammation, kidney failure and a rare blood disorder. Due to complications from lupus resulting in kidney failure, Wendy was on disability and unable to work. After nine years on a kidney transplant list, in 2009, she received a kidney from an anonymous donor. Wendy says, "Since my transplant, I have been

given a renewed quality of life, but the feeling that lupus is always there lurking and waiting in the background to wreak havoc will never leave me.” She adds, “I am tired of saying goodbye and seeing too many lives cut short by the disease.”

Note: *The case above is from a letter to [Selena Gomez](#), after the recording artist had a kidney transplant as a result of lupus nephritis, one of many complications of the disease. Gomez’s best friend donated the kidney, saving her life in the process.*

Additional case examples

- Monique Gorey-Massey: <https://www.youtube.com/watch?v=kjoK3HVF0GY>
- Rudy Villamar: https://www.youtube.com/watch?v=BroqyE25__s
- Josie Pierce: <https://www.youtube.com/watch?v=PgvrJAhJUa8>
- Taylor and Bonnie Kassell: <https://www.youtube.com/watch?v=LOnEJHhXUDo>
- Maurissa Tancharoen Whedon: <https://www.youtube.com/watch?v=FWIh1B0ndi4>

References

- CDC’s lupus web site—<https://www.cdc.gov/lupus/index.htm>
- National Institute of Arthritis and Musculoskeletal and Skin Diseases—<https://www.niams.nih.gov/health-topics/lupus>
- HHS Office of Women’s Health—<https://www.womenshealth.gov/lupus>
- National Resource Center on Lupus
 - [Diagnosing Lupus](#)
 - [Living with Lupus](#)
- Be Fierce, Take Control Campaign—<https://befiercetakecontrol.org>
- American College of Rheumatology—<https://www.rheumatology.org/I-Am-A/Patient-Caregiver/Diseases-Conditions/Lupus>
- Medicinenet, Lupus—https://www.medicinenet.com/g00/systemic_lupus/article.htm?i10c.encReferrer=&i10c.ua=1&i10c.dv=14
- WebMD—<https://www.webmd.com/lupus/guide/understanding-lupus-basics>