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Lupus\* has been described as 'the enemy within'; symptoms stir up images of a butterfly, a chameleon and a zebra. No two patients are exactly alike. Read on to understand more about the challenges of living with this condition.

## Attack

In lupus, the immune system attacks the patient's own body. No organ is entirely safe. The skin and joints are very frequently attacked; less often, the liver and eye.

## Bewilderment

It's bewildering to live with lupus since there are so many different symptoms and signs. Medics are also mystified, often misdiagnosing the condition.

## Celebrity

American singer and actress [Selena Gomez](#) [5] has spoken out about her life with lupus, after being diagnosed in 2013. "It was time to use my platform to help," she said.

In 2003, 'The Simpsons' aired an episode in which a 'Lupus Fun Run' took place to raise funds for research.

## Doctors

Because so many body parts can be attacked in lupus, it's likely that several different doctors will be involved in the diagnosis, including rheumatologists, immunologists, dermatologists, nephrologists, cardiologists and GPs.

## Echinacea

Often used as a dietary supplement to boost the immune system, it is advised against in lupus since it may cause the condition to flare.

## Flares

When symptoms suddenly worsen in lupus, it's known as a flare. Unpredictable in timing and intensity, it's possible that they are prompted by stress, sunlight and infection.

## Genetics

Lupus runs in families, though you've only a 3-10% chance of developing the disease if your family member has it.

## Heart

According to David Isenberg, Professor of Rheumatology at University College London, "lupus patients between the ages of 35 and 45 are much more likely to have a heart attack". Lupus affects the [heart and blood vessels](#) [6] in many ways: furred up arteries, for example, are frequently found in those with lupus. So the role of the cardiologist is vital.

## Imitator

Because of its vast and varied symptoms, lupus imitates many different diseases including rheumatoid arthritis, leukaemia and multiple sclerosis.

It's been called a chameleon because its "many disguises make it difficult to capture".

## Joints

Over 90% of patients with lupus develop pain and/or swelling in their [joints](#) [7]. It's often the first symptom.

## Kidney

After lupus attacked her [kidney](#) [8], Selena Gomez received a kidney transplant from her friend Francia Raisa in 2017. Gomez explained that their shared faith in God brought them together—and it's also what got them through one of the toughest moments of their lives.

## Life expectancy

Has greatly improved for lupus. In the 1950's, chances of five-year survival with lupus were only 50%. Now most patients can anticipate a normal lifespan, attributed to the advent of new drugs and kidney dialysis and transplantation.

## Music therapy

Is suggested to boost mood and lessen stress in lupus. Some [studies](#) [9] suggest that "the brain may respond to music almost as if it were medicine".

## Never lupus....

On the American television medical drama, 'House M.D.', Dr Gregory House utters the words "It's never lupus" to each junior doctor who, faced with a perplexing case, supposes lupus might be the diagnosis. One time, though, it is lupus.

## Oxygen

Lupus affects the [lungs](#) [10] in many ways; some patients require oxygen therapy. Pleurisy and 'shrinking lung syndrome' are two possible lung problems.

## Pain

[Pain](#) [11] is a common problem in lupus; inflammation, fibromyalgia and depression may be associated.

## The rash associated with lupus is often, but not always, exacerbated by sunlight

## Questions

Many questions remain concerning the cause of lupus. Genetic, hormonal and environmental causes probably conspire together.

## Rash

Lupus derives its name from the Latin for 'wolf' since a rare facial rash resembling a wolf's bite is possible; more common is a so-called 'butterfly rash', named after its shape across the face.

## Sunshine, seizures

The rash associated with lupus is often, but not always, exacerbated by sunlight. Staying in the shade is suggested.

Seizures are also possible as lupus can attack the brain.

## Treatments

There is no cure, but symptoms may be substantially reduced with steroids, anti-inflammatory drugs such as ibuprofen, immunosuppressant drugs and even anti-malarial drugs (found by chance to be effective for lupus in the 1950s).

## UK

Around 50,000 people are thought to have lupus in the UK. [Lupus UK](#) [12] is the only national charity supporting and informing people with lupus.

## Vomiting

During a lupus flare, you may experience loss of appetite, weight loss and even vomiting.

## Women

Between the ages of 15 and 50, women are much more likely to get lupus than men; sex hormones are thought to play a part in the disease process.

## Xtreme tiredness

Fatigue is a profound problem in lupus, even after a good night's sleep.

## Young people

Diagnosis is most common between the ages of 15 and 50, but about 20% of patients are diagnosed in childhood.

## Zebras

Rare diseases, such as lupus, are often referred to as '[zebras](#) [13]' in medical jargon. It's because, in diagnosis, medical students are instructed to "think of horses not zebras when you hear hoofbeats". (In other words, opt for the obvious diagnosis, since horses are more common than zebras.) When it comes to lupus, though, the commonplace may not be correct: the rarer and less expected may actually be right.

\*Systemic lupus erythematosus



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Source URL: <https://www.helencowan.co.uk/z-living-lupus>

### Links

[1] <https://www.readersdigest.co.uk/health/health-conditions/an-a-to-z-of-living-with-lupus> [2] <https://www.helencowan.co.uk/./tags/heart> [3] <https://www.helencowan.co.uk/./tags/kidney> [4] <https://www.helencowan.co.uk/./tags/immunity> [5] <https://www.hellomagazine.com/healthandbeauty/health-and-fitness/2017091442412/what-is-lupus-selena-gomez-condition/> [6] <https://resources.lupus.org/entry/heart-and-circulation> [7] <https://resources.lupus.org/entry/joints-muscle-pain-in-lupus> [8] <https://www.hopkinslupus.org/lupus-info/lupus-affects-body/lupus-kidneys/> [9] <http://www.mollysfund.org/can-inspirational-songs-heal/> [10] <https://www.hopkinslupus.org/lupus-info/lupus-affects-body/lupus-lungs/> [11] <https://www.lupusuk.org.uk/pain-management/> [12] <https://www.lupusuk.org.uk/> [13] <http://www.findzebra.com/>