

# The Silent Killer



I was her favorite, and she was mine. She was the aunt who always seemed to understand me. We were alike, and I looked up to her even though she was so much older. “Shorten that skirt,” I can still hear her deep, melodic voice saying to me as I stepped out of my parents’ car about to ascend the stairs into my auntie’s arms. It always seemed to be that way, her welcoming me with a big smile and a sassy attitude. I recall her saying something like, “You’re young, and young girls need to show off their pretty legs while they still have them before they turn flabby like mine.”

It was not at all true. She had a beautiful figure for her age. However, now that I think about it, I never really knew exactly how old she was until I saw the dates printed on her funeral program and did the math. They read, “Sunrise 1952 and Sunset 2001.” That would make her 49 when she died.

In 1999 my aunt was diagnosed with Systemic Lupus Erythematosus (SLE). When I finally found out, she had been continuously fighting and losing a serious battle for over a year. According to Usinlupus.com, Systemic Lupus is an autoimmune disease where the immune system attacks and destroys healthy tissue because it can no longer tell the difference between

invaders and healthy tissue. A person diagnosed with lupus has an overactive immune system, which produces excessive amounts of blood proteins.

This disease has many nicknames. It is often referred to as a “stealth disease” because of its deceptive and complicated nature. It is also called the great imitator because it is hard to diagnose. This is because its symptoms often mimic other disorders causing the disease to be commonly misdiagnosed. This is why Lupus is also referred to as “the silent killer.”

When I was 15 years old, my aunt told me that she was moving to California. California was a whole different world to me at the time. She promised to keep in touch and visit for Christmas. She kept her promise as always and came home that year, and it seemed, she was the same lively, happy person she always was. It seemed my entire family met at her house that year she came home for Christmas. We were all laughing and joking like we always did, almost as if she had never left. After a couple of hours, her demeanor began to change. She became a little distant, preoccupied. I found a moment alone with her in that crowded house on Christmas Day. I hugged her and asked her how she was doing. She smiled and said something like, “I see you stopped wearing those long skirts.” I smiled. That was enough to convince me that she was still her sassy self, and I thought everything was alright. I was wrong.

I imagine that if my aunt could have brought herself to tell me about her pain, she would have been inclined to mention chronic fatigue, chills, and fevers, the skin rash across her nose in the shape of a butterfly<sup>1</sup> that I never saw. She would have had to mention the many infections or the emotional trauma of spending many nights in a hospital bed not knowing what caused her to

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<sup>1</sup> According to Lupus.org, when the rash is present without other symptoms of systemic lupus it is called cutaneous lupus. The butterfly rash in systemic and cutaneous lupus can appear after exposure to sunlight on the cheeks and nose and can cause scarring once healed. cutaneous lupus can form on the arms, neck, face and scalp.

become so sick or the depression of having to deal with such a complex disorder. I would have listened to her doctor explain the inflammation, redness, swelling, and pain of her kidneys, joints, lungs, heart, or maybe even her brain. Instead, she spared me, her favorite niece, all the pain and sadness that I know I would have experienced if she would have revealed to me the real answer to the question I asked every Sunday during our regular conversation. “Hi Auntie, how are you doing?” Week after week, she filled my ears with wonderful stories about how much she loved her new life in California. She told me about all the famous people she had seen and all the places she shopped.

She would not be able to make it home the following Christmas she was sick—just a little cold, she said, but it was too much to travel. I remember my father seemed very worried after that conversation. It was just a cold, I thought. Were they keeping something from me? If something were wrong, they would tell me, I thought to myself; after all, I was not a kid anymore. Again, I was wrong. My father later told me that my aunt was in the hospital that Christmas and that she was very sick. “She has lupus,” he said.

I quickly began to research this unfamiliar disease. I wanted to force my aunt to give me details, to tell me exactly what she was feeling, but I could not talk to her. She was unavailable for the first two weeks that I began research on the disease. I was on my own.

Lupus in Latin means wolf, and erythematosus means redness. The disease receives its name from the skin damage it leaves its victims that resemble a wolf’s bite. This wolf’s bite is actually a facial lesion or skin ulceration. During a conversation with my grandmother, I asked her about any skin damage my aunt may or may not have had. My grandmother went to California to visit

my aunt often. She told me that my aunt did have this mark from the disease and that she was very sick.

The immune system is supposed to protect the body against foreign agents. Lupus is an autoimmune disease characterized by the body's immune system turning against the body. Autoimmunity happens when B cells, which circulate through the body in search of an infection to destroy by creating antibodies, mistake the body's healthy cells for these foreign infections. The T cells, which are supposed to tell the B cells when to stop making antibodies, fail to do so. The B cells are the body's protectors, destroying anything that may harm the body. T cells are the information systems, telling the B cells what is foreign and what is not. When they do not do their job, the immune system goes awry, resulting in diseases such as lupus and the Human Immunodeficiency Virus (HIV). Lupus is so hard to diagnose because there is no standard set of symptoms. Doctors have found that each Lupus patient is different.

Genetic predisposition and the environment play large roles in the development of the disease. According to Lupus.org, 20% of Lupus patients have a sibling or parent with the disease. Environmental factors, such as the sun, exposure to silicone, or certain medications, must be present to trigger symptoms.

When reading this information, my mind immediately went to my aunt and all the stories she told me about California; how much she loved going to the beach, going to Disney Land, and shopping. All the things she loved involved the sun. The heat never seemed to bother her before. It's amazing that after 49 years of loving the sun, the sun could have possibly played a part in killing her.

According to the CDC.org, 9 out of 10 people diagnosed with Lupus are women, and the disease is three times more common in African American women than in Caucasian women. Lupus has a 90% survival rate but is often more fatal in African Americans in general. Black women tend to develop Lupus at a younger age, and they tend to experience the harsher symptoms associated with the disease. Many scientists believe that this is due to a group of genes that are more prominent in African Americans<sup>2</sup>.

I imagine my aunt going through emotional changes as her body was set on destroying itself. Many people with Lupus experience mood disorders, depression, hallucinations, or general psychosis. I asked my grandmother if she noticed any changes in my aunt's behavior, and she began to tell me a story about one of my aunt's good days with the disease. People with Lupus tend to have good and bad days. The bad days are usually characterized by what doctors refer to as "flare-ups," where many disease symptoms become active. Flare-ups typically occur when things such as the sun or stress trigger these symptoms. Good days are characterized as days with no flare-ups.

Sometimes I sit and wonder what happened, and I'm sure my aunt asked this same question over and over again, in those days and nights in the hospital, that time of crisis, chills, fever, infection? Many people with Lupus fall into a deep depression. They feel as though their lives are over and that this horrible disease has defeated them, but not my aunt. She remained strong and determined to lead as close to normal life as possible.

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<sup>2</sup> According to Lupus.org, there is still a lot of research being done in this area, but environmental factors and hormones also play a role in who is affected by lupus and how the disease effects their bodies.

Did her decision to continue to live her life as she desired, knowing that she would be sick for the rest of her life, stress her out? There is currently no cure for Lupus, but there are medications that treat each symptom of the disease. Some of the medications prescribed for the symptoms, such as corticosteroids,<sup>3</sup> can cause hair loss and weight fluctuation. These side effects, coupled with stress or depression, can cause anyone to give up on life, but not my aunt.

Did the realization that she would have to limit many of the things she once enjoyed involving the sun make her sad? UV light causes antigens, which are protein molecules, to form on the surface of skin cells. This causes antibodies to latch onto the skin and attract white blood cells, which attack the skin cells, causing the rash. It is believed that, after the onset of lupus, patients are exposed to sunlight, their skin creates an extreme amount of nitric oxide, causing the inflammation and swelling of these lesions. These grotesque marks could have damaged the self-esteem of any human being, but not my aunt's. I can hear her now, "I will put on long sleeves and a hat, and I will be just fine."

Systemic Lupus is just one of the four forms of Lupus erythematosus. Discoid Lupus (DL) and Drug-induced Systemic Lupus (DILE) are the other forms that complete the group. Patients diagnosed with Discoid Lupus can breathe a sigh of relief because it is only characterized by a skin rash. This type of Lupus comes with no risk of damage to vital organs and rarely leads to systemic Lupus. The skin rash is a chronic condition that involves crusty, scaly patches that are often circular and red. These patches can heal within weeks with proper treatment but may scar. This form of Lupus can appear anywhere on the body but is common on the face, ears, or scalp.

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<sup>3</sup>According to Medicine.net, corticosteroids are hormones that suppress the immune system. Normally the body produces these in adrenal glands, but when the body is attacked by a disease such as lupus the kidneys do not make enough cortisone, which is an adrenal hormone to reduce the inflammation.

When Discoid Lupus is found in areas involving a lot of hair, such as the scalp, it usually leads to permanent scarring and hair loss.

Drug-induced Lupus is exactly what its name implies, a form of Lupus caused by the use of certain drugs. It occurs after certain medications are used for an extended period of time. This type of Lupus is characterized by extreme fatigue and swelling of the muscle and joints, serositis (inflammation around the lungs and heart), and flu-like symptoms. Symptoms gradually go away once the medication is stopped. Medicines used to treat heart disease, thyroid disease, neuropsychiatric disorders, and many other drugs have been found to cause Drug-Induced Lupus. According to the Lupus Foundation of America, Inc., there are at least 46 medications that have reports of this type of Lupus as a side effect. Drug-induced lupus is more commonly associated with Procainamide (Pronestyl), Hydralazine (Apresoline), and Quinidine (Quiniglute). It usually takes several months or years of taking these medications for Drug-Induced Lupus to appear.

There is a great chance that if my aunt were diagnosed with discoid lupus or drug-induced Lupus at 47 instead of systemic lupus, she would still be alive today. Or even if she were diagnosed with systemic lupus at a younger age, she may have had a fighting chance. However, being diagnosed with other types of Lupus is no cakewalk. All three types come with different battles to overcome.

I remember the first conversation I had with her after she had been diagnosed. “How are you, Auntie?” I asked, as I always did every Sunday, but I tried to keep the anxiety and anger out of my voice this time. I was filled with so many emotions that day. I remember it was raining, and I thought what appropriate weather for this conversation. I rehearsed that conversation over and over again in my dorm room the whole week before. I would start by asking questions of

concern like: When did you find out? How serious is it? What are your symptoms? To eventually lead up to questions like: How long have you known? When were you going to tell me? Who else knows about this?

But it went nothing like that. My aunt told me she was doing great. “Auntie, I want to know about the disease. I want to know everything you haven’t told me.” She didn’t miss a beat.

“Why should I talk about sadness when I’m so happy? Enjoy life, sweetie, I am.”

She refused to tell me about the kidney disease<sup>4</sup> and her many hospital stays. She did not want to give me any reason to worry, but it did not work. I constantly worried about her. No one in the family seemed to talk about her disease much.

Today, people can live relatively normal lives with Lupus. According to the Lupus Foundation of America, with treatment and regular doctor visits, 80 to 90% of people with lupus can also expect to live a normal life span. Treatment of the disease can minimize symptoms and reduce inflammation, but that is all. It will not conquer the disease and give the immune system back the knowledge it needs to determine the body’s tissue from infection. It will not stop the disease from disrupting the patient’s life anytime it feels the need to do so. This disease caused my aunt’s body to be self-destructive for many years. When she was finally diagnosed and began treatment, there was already years of damage done. If my aunt had been diagnosed and ultimately treated earlier in her life, the disease may not have killed her. Had she been diagnosed today, with the many advances in Lupus research and the health industry in general, she may have been able to live another 20 years.

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<sup>4</sup> According to the Lupus Foundation of America, 60 percent of people with lupus eventually develop lupus-related kidney disease, known as lupus nephritis. If not treated successfully, it can lead to kidney failure.



Treatment for the disease can be different with each patient because it is based on an individual's symptoms and personal needs. However, there is common treatment prescribed for Lupus patients, consisting of preventive methods:

- Exercise to keep the muscle from becoming weak and prevent fatigue,
- avoidance of the sun and
- immunizations to prevent infections.

Psychological measures are suggested as well and include:

- Support groups, counseling, talking to friends, relatives, and doctors to alleviate the effects of stress and depression,
- and coping mechanisms to deal with constant body changes.

Medicines are also prescribed in the treatment of Lupus. Many include:

- Acetaminophen used to suppress pain,
- Corticosteroids used to reduce inflammation and stop the activity of the immune system,
- Antimalarials are commonly used to treat Malaria and are used for skin irritations or joint pain.
- Anticoagulants, which are used to make the blood thin to reduce blood clots.

All these medications come with an array of side effects. According to the Lupus Foundation of America, these side effects can include less severe problems, such as acne, weight gain, and easy bruising. They also have more severe ailments such as reduced blood flow to the kidney, osteoporosis, high blood pressure, cataracts, diabetes, infection, stomach ulcers, an increase of appetite, anemia, low white blood cell count. For many of these medications, their use may predispose an individual to develop cancer later in life.

Lupus is the silent killer, and although it killed my aunt, it did not silence her. She was sassy, strong-willed, and determined all her life, and the disease did not stop that. Ever since I can remember, my aunt always did the things she wanted to do. My parents said no eggnog for me; she slipped some in my cup. Her husband said no more clothes this month; you've got enough; we went shopping. It was comforting for me to know that she remained that way until the end of her days because when Lupus said, lie down, you're tired, she went on a shopping spree. The disease said, give up; you can't fight me. She laughed and went to work.

### References

Lupus Foundation of America, Inc. "What Does Lupus Erythematosus Mean." N.d. <https://www.lupus.org/resources/what-does-lupus-erythematosus-mean#> Accessed 12/21/2020.

US in Lupus. "What is Lupus." N.d. [https://www.usinlupus.com/basics-of-lupus/what-is-lupus?cc=ps\\_6EKHKGXP4H726346&mcm=60003&gclid=EAIaIQobChMIgZq8g-CC7gIVA4SGCh0IIAhaEAAYASABEgLMxID\\_BwE&gclsrc=aw.ds](https://www.usinlupus.com/basics-of-lupus/what-is-lupus?cc=ps_6EKHKGXP4H726346&mcm=60003&gclid=EAIaIQobChMIgZq8g-CC7gIVA4SGCh0IIAhaEAAYASABEgLMxID_BwE&gclsrc=aw.ds). Accessed 1/4/2021.

Fight Like a Girl Club. "Lupus Symptoms: The Silent Killer." 6/1/2019. <https://www.fightlikeagirlclub.com/lupus-symptoms-the-silent-killer/>. Accessed 12/28/2020.

Center for Disease Control and Prevention. "Lupus in Women." 7/13/2018. <https://www.cdc.gov/lupus/basics/women.htm>. Accessed 12/28/2020.

Omudhome Ogbu. "Corticosteroid Drugs: Systemic, Oral, Injections, and Types." N.d. <https://www.medicinenet.com/corticosteroids-oral/article.htm>. Accessed 1/2/2020.

Lupus Foundation of American. "African Americans and Lupus." 2013. <https://www.lupus.org/s3fs-public/Doc%20-%20PDF/Ohio/African%20Americans%20and%20Lupus.pdf>. Accessed 12/28/2020.