The Question We’re Afraid to Ask: Can Lupus Be Fatal?

by BARBARA LEECH

Complications and Fears — Is Lupus Fatal?

Having lupus is not what many people imagine it to be. I find that people either have no clue what it is (or what it does) or they think you are about to die.

We warriors live with these reactions on a regular basis. We try to educate those who do not understand. We often avoid the question about whether lupus can be fatal.

The fact is, lupus can be fatal. Those of us who fight this fight every day know this and often fear what the next unexpected complication will ultimately do to us.

We go back and forth in an emotional battle of facing our own mortality, determined not to let lupus kill us, while fearing we really have no power to stop it.

That is one of the hardest parts of this disease — the unknown, which can appear out of nowhere. You are OK one minute, and suddenly you have mysterious pain and swelling and you wonder if this is the beginning of what could be the end.

Focus on Facts

With early diagnosis, medication and preventative treatments, many of us with lupus are living longer lives. In fact, with careful treatment, 80 to 90 percent of those diagnosed with lupus can expect to live a normal lifespan. This gives us hope.

But, if left untreated, and sometimes just because the disease is stronger than we are, lupus is potentially fatal.

It can cause serious, life-threatening conditions, including kidney disease, pancreatitis, pleurisy, vasculitis, pericarditis, and cancer. Ultimately, lupus is capable of damaging your organs and causing them to completely fail.

So, those of us fighting this war on our bodies live in fear of what the next attack will bring and which organ it will target. We realize that if enough attacks happen, this could be how we die.

We look for any signs of the next attack before it fully arrives. We examine and weigh every symptom for its lethal potential.

And lupus can cause many devastating, life-altering, symptoms. Things you could not have imagined happening to you suddenly happen.

It has no boundaries, possessing the ability to affect nearly every organ in the body without warning, which

causes widespread infections and inflammation.

The Most Common Dangers of Lupus

- **Kidneys are the organs most commonly affected by lupus; this is called lupus nephritis.** Long-term inflammation in the kidneys causes permanent damage. If enough of the kidney becomes scarred, it will begin to lose function.
- **Lupus can also cause inflammation of the heart.** This can result in an increased rate of heart attacks and arterial disease, even in young patients.
- **Some people with lupus also have antiphospholipid antibody syndrome (APS or Hugh syndrome).** APS increases the risk of developing blood clots that can occur anywhere in the body, including the legs, lungs, or even in the brain.

Lifesaving Drugs and Treatments

As a lupus warrior, you get tired of doctor appointments, hospitals, the lack of knowledge about the disease that some ER professionals still struggle with, and medications that do not always work. And often, while medications are trying to work, they make you feel more certain that death may be forthcoming.

You feel far worse before you feel better. There is no pill to take that quickly makes you recover.

So, if you are like me, you find yourself grateful for there being treatments, yet rightfully concerned that the treatment won't work for you. You worry if the doctor overseeing this deadly flare has the skills and knowledge needed to make the right choices.

With lupus, there are so many variables and differences in the disease from person to person, so treatment can feel like a guessing game.

But thankfully, there are several treatments that can help limit flares and organ damage, reduce inflammation, and ease some of the pain associated with the disease. None of them work perfectly or even work for all lupus patients, but these are the most common medications and treatments prescribed:

- **Anti-inflammatory drugs.** Many over-the-counter NSAIDs, such as naproxen (Aleve) and ibuprofen (Advil, Motrin), are used to treat pain, swelling and fever associated with lupus.
- These are effective in the reduction of swelling, warmth, pain, and tenderness associated with lupus inflammation. Steroids are the most common medicines used to treat lupus flares.
- **Antimalarial drugs.** These relieve pain in the joints and muscles, improve skin rashes, help avoid inflammation of vital organs and their linings, improve other symptoms associated with lupus such as fever and fatigue, prevent the spread of lupus to other organs, and can cause a 50 percent reduction in flares.
- **Immunosuppressants.** These are drugs that suppress the immune system, and may be helpful in more serious cases of lupus or cases where the lupus is very active. Potential side effects may include an increased risk of infection, liver damage, decreased fertility fatigue, nausea, and diarrhea, mild pain in your arms and legs, or mild cold symptoms and an increased risk of cancer.

Read more about your lupus medication options in this article from Anna and Barbara.

Lupus Can Be Fatal, but the Odds Are in Our Favor

Up to 1.5 million Americans are afflicted by some form of lupus, while more than five million people are known to be affected worldwide. Each year more than 16,000 Americans are newly diagnosed with the disease.

Many of us worry that this disease will win the battle and we will lose our lives. Some of this is facing the reality that people do die from this disease, but we must focus on the fact that most lupus patients can live a normal lifespan.

Because lupus was not well understood in the past, those who had lupus died younger, usually of problems with vital organs. But today, medicine, treatments and a better understanding of the disease means it can be managed more successfully.

There is great hope that most will keep the wolf at bay and live their normal lifespan.

Does this ease a lupus warriors mind? A little bit. I think we all have moments where we wonder if we will be part of those fatal statistics, but it is important to focus on the fight and to keep our faith. The odds are in our favor.