THE LUPUS JOURNEY:

NAVIGATING LIFE AS A BLACK LUPUS WARRIOR

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FINDING ANSWERS IN A SEA OF QUESTIONS

Lupus is complicated.
It can show up in quiet ways at first:

- Tiredness that doesn't go away
- Strange Rashes
- Nagging Joint Pain
- And for many, it takes far too long to get real answers.

While anyone can be diagnosed with lupus, **Black Americans are nearly three times more likely to live with this chronic illness.** Women are 9 times more likely than men to be affected – usually at a younger age, and often with more serious symptoms.

That's why this guide was created:

To help you feel seen, informed, and supported. Whether you're newly diagnosed, trying to make sense of your symptoms, or just want to better understand lupus for yourself or a loved one, this eBook is here for you.

WHAT LUPUS CAN LOOK AND FEEL LIKE

Lupus doesn't have a single known cause, and right now, there's no cure. But what we do know is that early diagnosis and treatment can make a real difference. The sooner you recognize the **signs, like rashes, fatigue, and joint pain**, the better your chances of managing symptoms and avoiding complications down the road.

Treatment isn't one-size-fits-all, but it can help reduce flares and protect your organs. Managing lupus also means **paying attention to the things that trigger your symptoms, whether that's stress, certain foods, or even the weather.** With the right care and knowledge, you can live well with lupus.

WHY THIS MATTERS SO MUCH IN OUR COMMUNITY

Lupus doesn't play fair—and for Black communities, the stakes are even higher. **One in 250 Black women will be diagnosed with lupus.** And yet, it still takes many of us years—sometimes up to six—to get a proper diagnosis. That delay isn't just frustrating, it can be dangerous.

For Black patients, the signs of lupus—especially skin changes—may not look the same as they do in other groups. This can lead to misdiagnosis or doctors brushing off symptoms. And too often, Black patients aren't heard or believed, especially when it comes to pain. That makes it even harder to get the care we need.

Many of us rely on community clinics for healthcare. These centers play a vital role, but they may not always have the knowledge and resources to suspect or diagnose for complex diseases like lupus. As a result, some people don't realize what's going on until things get worse.

The consequences of late diagnosis can be serious—kidney damage, nervous system issues, and heart disease are all risks that go up when lupus goes untreated. And since many Black people already face a higher risk for these health problems, lupus just adds another layer.

That's why it's so important to have resources like this. You deserve to understand what's happening in your body. You deserve to be taken seriously. And you deserve to have the tools to advocate for your health every step of the way.

CHAPTER 1:

UNDERSTANDING LUPUS

WHAT IS LUPUS?

Lupus is a chronic autoimmune disease in which your immune system malfunctions. Instead of keeping infections at bay, your immune system will treat healthy tissues as the enemy. As a result, in people with lupus usually have healthy tissue and organs are under attack. The longer your condition goes untreated, the more likely you are to have permanent damage.

THERE ARE ALSO DIFFERENT TYPES OF LUPUS. THESE ARE:

Systemic lupus erythematosus (SLE)

This is the most common form of the condition as it affects up to 70% of the people who have lupus. In this form, inflammation can involve several organs and tissues throughout the body.

Lupus nephritis

Is a form of SLE, inflammation is focused on the kidneys. As a result, you're likely to suffer from kidney inflammation and damage.

Cutaneous lupus

If you have cutaneous lupus, the disease will mainly affect your skin, and you'll see rashes and lesions without organ involvement. It includes several types of rashes, some cause permanent damage (scarring) while others do not.

Discoid lupus

Discoid lupus is the chronic form of cutaneous lupus, and has been found to affect Black people predominantly. Black Americans are four times more likely to have it than other ethnicities. With this one, you can get rashes that look like discs on your scalp or face. When they become sores, they're usually red and scaly. Having discoid lupus can also result in scarring, scaly patches of skin, and hair loss.

Drug-induced lupus

Though it's not as common, certain drugs can cause lupus as well. In most cases, the symptoms disappear when you stop taking the medication that caused them.

Incomplete lupus

Patients who have lupus, but do not meet the criteria for SLE

Neonatal lupus

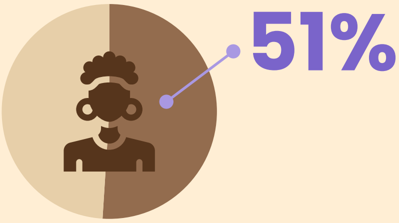
This form of lupus usually affects infants who are born to mothers who have SLE.

HOW LUPUS HITS US HARDER—AND EARLIER

According to multiple studies, Black Americans need to be more aware of lupus than other racial and ethnic groups. Though Black people in general are three times more likely to develop the condition, it's women who face the brunt of it. **Up to 1 in 250 Black women will be diagnosed with lupus, which is three times higher than the prevalence in white women.**

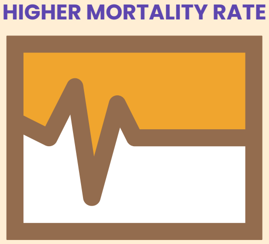
While the age range for developing lupus is between 15 and 44, **Black Americans are known to be diagnosed with it at an earlier age.** Additionally, Black people are more likely to have more severe symptoms and have more complications.

In a wide-reaching study, researchers found that Black Americans were twice as likely to have complications from lupus that affected their kidneys, nervous system, liver, and blood. When it comes to lupus nephritis, the **study shows that Black people are up to 51% more likely** to develop this form of chronic illness. By comparison, white people have a prevalence of 13 to 23%.



There is also a significant difference in how lupus symptoms can manifest in Black people. For example, during a study, 45% of the white participants had a malar rash and 54% of them had photosensitivity. None of the Black participants had those symptoms. In contrast, 52% of the Black Americans had alopecia while only 11-39% of the white participants experienced that symptom.

In a study conducted by the Lupus Foundation, Black women also have a higher mortality rate than other ethnicities. They're also more likely to die at a younger age. Once they excluded common external causes of death, researchers found that complications from lupus were the fifth leading cause of death in those who were between the ages of 15 and 24. It's the sixth and eighth cause of death in Black women in the age ranges of 25-34 and 35-44, respectively.

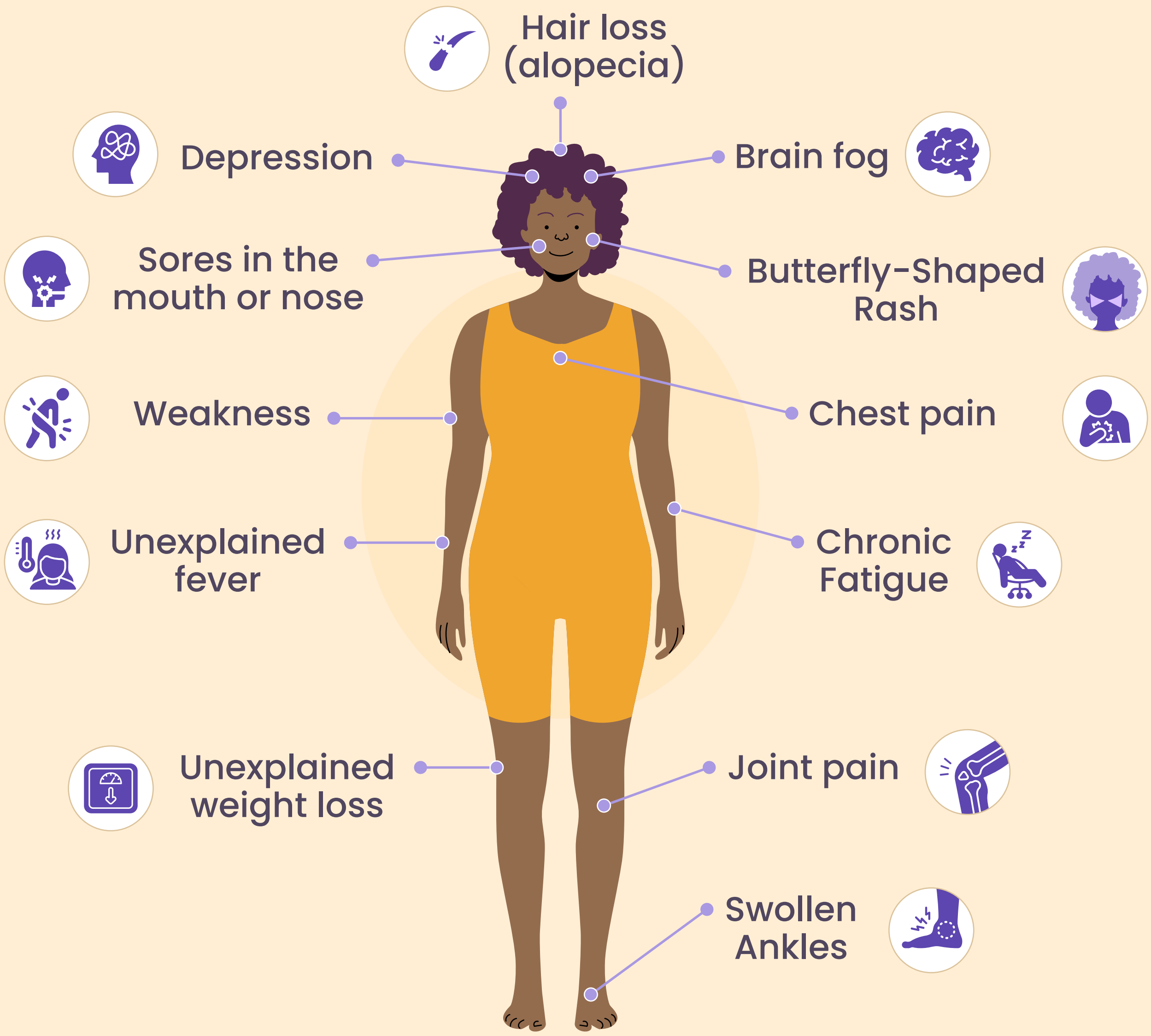


Lupus can also have a socioeconomic impact on Black Americans. Living with lupus may mean having fewer days of productivity and not being able to hold a full-time job. In general, up to **55% of people with lupus stated that they had lost most or all of their income because of the disease.** Furthermore, 1 in 3, have a temporary disability, and 1 in 4 have a permanent disability that warrants receiving disability payments.

CHAPTER 2:

RECOGNIZING THE SYMPTOMS

COMMON SYMPTOMS OF LUPUS



Lupus can be difficult to diagnose at its early stages because it might not exhibit many symptoms. If it does, **some common symptoms at that stage can be weakness, joint pain, an unexplained fever, fatigue, and unexplained weight loss.**

Another characteristic symptom of lupus is a rash across your cheeks and nose that looks like butterfly wings. This rash often gets worse when exposed to sunlight. On lighter complexions, the rash can appear to be red or pink, but looks dark brown or purple on darker skin.

As the disease progresses, there may be additional symptoms. However, it’s important to note that the severity of these symptoms may vary from one person to the other and they may not appear at the same time. Some symptoms may also worsen over time, others remain unchanged, other might improve for a while.

You may experience aching joints swollen joints, constant fatigue, skin rashes, brain fog, swollen ankles, chest pain, hair loss, sensitivity to light, seizures, sores in the mouth or nose, and pale or purple fingers when you're cold or stressed. If you're wondering if you have lupus, this symptom checker may be able to help, and ask your doctor to test you for lupus.

When lupus affects the skin, it **can cause rashes and blisters on your skin as well as mouth sores and hair loss.**

When your immune system attacks your joints, you may develop arthritis. The resulting joint pain and stiffness may be temporary or permanent.

Other organs that can be affected by lupus are your kidneys. When your kidneys are damaged, you may also develop high blood pressure that needs to be controlled with medication. Despite that, it's common for people with kidney damage to need a transplant. Frequent urine tests with your physician is extremely important in this case.

In some situations, lupus can cause problems with your brain and spinal cord. If that happens, you may experience brain fog, or more rarely confusion, depression, seizures, numbness, and weakness.

If the condition causes inflammation of the tissues surrounding your heart and lungs, you may have chest pain and an uneven heartbeat. Fluid may also build up around your heart and lungs, causing shortness of breath.

Finally, lupus can affect your blood. It's common for people with the condition to have significantly low red blood cells, white blood cells, and platelets. These low numbers can result in fatigue, easy bruising, and susceptibility to serious infections. You may also be more likely to have blood clots, which can develop in your legs or in your brain to cause a stroke. Interestingly, you may not notice these symptoms, so it's essential to undergo regular blood tests.

UNIQUE CHALLENGES IN BLACK PATIENTS

Black people generally face certain challenges when dealing with lupus. **While lupus may not be easy to diagnose, Black Americans face a longer delay than others.** One issue that contributes to that is how different the symptoms can be for Black people.

For example, unexplained skin rashes are characteristic of the condition, but look different on Black skin. People with lighter skin might have rashes that are red or pink, but Black Americans get rashes that appear purple or dark brown. Additionally, **Black women are more likely to develop these rashes on their scalp and ears than other ethnicities.** This makes it easier to miss or attribute to something else.

Those who have the lupus-related rash on their scalp are also more prone to alopecia, so that explains why Black people experience hair loss with lupus more than other ethnicities. Black Americans are more likely to have rashes and blisters that leave permanent scarring or darkened skin behind.

Lupus complications are also more likely to develop in Black people. Most notably, **Black Americans have higher rates of kidney damage than other ethnicities and end up in renal failure.** However, the most common cause of death for Black people with lupus is cardiovascular disease.

A recent study found that Black people are 7 times more at risk for a cardiovascular issue like a heart attack or stroke within the 15 years following their lupus diagnosis. In that time span, the risk of a cardiovascular event can be as high as 19 times higher than in other ethnicities.

A different study also found that **Black Americans were more likely to have neuropsychiatric lupus (NPSLE) after being diagnosed with SLE.** People with this form of the condition can experience headaches, mood disorders, cognitive impairments, seizures, and strokes.

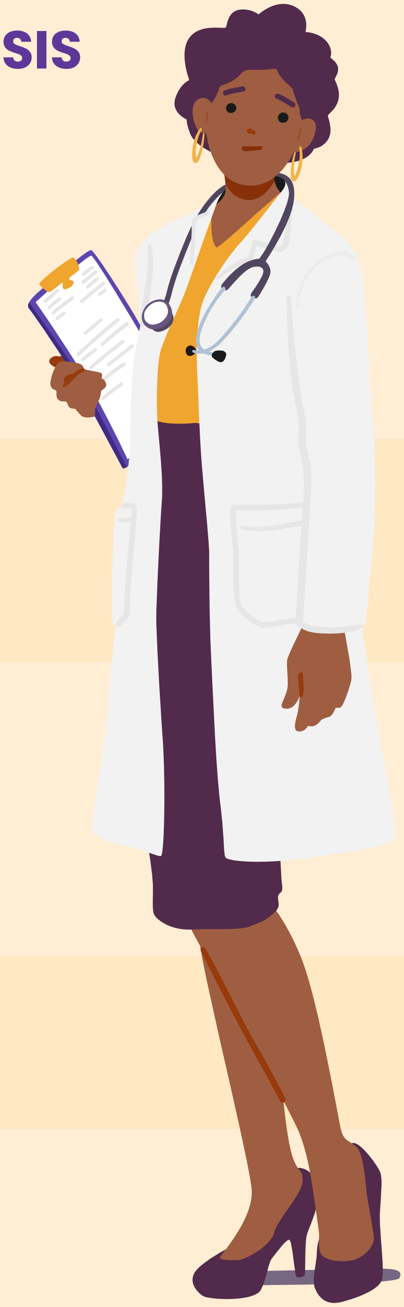
IMPACT OF DELAYED DIAGNOSIS

Though Black Americans have been shown to have more severe symptoms and worse outcomes, a delayed diagnosis can play a role in those outcomes. **Lupus can't be cured, but the symptoms can be managed so that you don't permanently damage your skin, joints, or organs. That means an early diagnosis is integral to living well with lupus.**

Without an early diagnosis, you're more likely to develop complications from the disease. **If it affects your joints, you may have permanent joint damage** that makes it difficult to use your hands and leads to a disability.

Major health problems like strokes, heart attacks, and renal failure can further affect your ability to maintain quality of life and employment. As mentioned previously, many people with lupus lose money because they can no longer work full-time. In the worst-case scenario, these issues will be fatal.

Even the common symptoms of lupus, like **headaches, joint pain, and chronic fatigue can steadily corrode your employment options.**



CHAPTER 3:

WHY LUPUS HITS THE BLACK COMMUNITY HARDER

GENETIC AND BIOLOGICAL FACTORS

Though doctors aren't sure why Black Americans have a higher predisposition for developing lupus, researchers suggest that it could be a combination of genetics, hormones, and environmental factors.

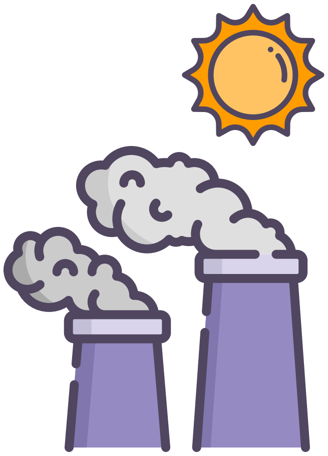
According to several studies, certain genes may influence proteins that then affect the immune system. For example, major histocompatibility complex (MHC) genes are typically linked to lupus. There are currently two families of MHC genes that are associated with lupus - the **MHC class II and MHC class III. Researchers believe that these genes play a significant role in Black people's higher risk of lupus.**

Another genetic factor that you should know about is the Apolipoprotein L1 (APOL1) gene. This gene is linked to an increased risk of lupus-related kidney disease and death in people of African ancestry. It's believed that this gene makes it more likely for Black people to develop lupus nephritis and lead to more severe damage. **Furthermore, if you have this gene, you may have significant kidney damage before experiencing any symptoms of the condition.**

Where hormones are concerned, doctors continue to look into why women are more likely than men to develop lupus. Though more research needs to be done, doctors suggest that estrogen may explain the difference. **It's estimated that the effect estrogen can have on the immune system may make the effects of an autoimmune condition worse.**

Additionally, some patients with lupus experience worsening symptoms during menstruation. However, there is conflicting information regarding whether or not this can solely be attributed to fluctuations in estrogen.

ENVIRONMENTAL TRIGGERS



When it comes to your environment, it can be involved in the development of lupus and triggering flares. For example, stress might not cause lupus but **many people experience their first significant lupus symptoms after a period of extreme stress**. It's usually what leads them to seek a diagnosis.

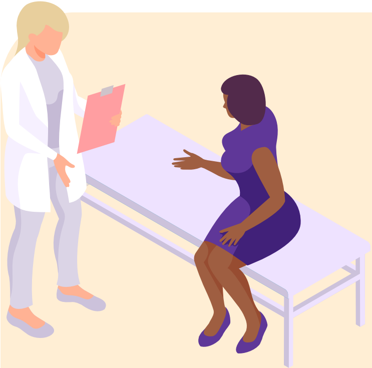
Sunlight is also a common trigger for lupus symptoms. Before being diagnosed, people with the condition may describe being drained or feeling exhausted after exposure to sunlight. The length of the exposure generally shouldn't be enough to cause dehydration or any of the other conditions that could lead to those symptoms.

Infections are also thought to trigger lupus, the most important is the association with EBV, the Epstein Barr Virus.

With chemicals and pollutants, the association with lupus isn't always clear. **Some toxins, such as cigarette smoke and mercury, have already been linked with cases of the condition.** Silica, in particular, has been identified as a significant environmental factor in developing lupus.

According to a recent study of the link between lupus and environmental issues, **it was found that persons who are exposed to silica at work are up to five times as likely to develop lupus.** The risk of silica exposure lies in the fine dust from rock or sand, or in products such as pottery, ceramics, or tile dust.

Other chemicals you need to be wary of are the pesticides you use at work. In the same study mentioned above, researchers found that those who worked with long-term pesticides frequently had a higher chance of developing lupus.



HEALTHCARE INEQUITIES

Though lupus is more prevalent in Black Americans, that doesn't mean they receive the same level of care as other races and ethnicities. In fact, some **studies show that Black people consistently receive delayed diagnoses and experience inequities in treatment.** Patients often describe dealing with racial bias, limited access to the specialists who can help them, and dismissive attitudes about their symptoms.

Access to specialists when dealing with lupus is a critical part of care. This is because of the different organs that the condition affects. People who have persistent skin rashes will need to see a dermatologist ,while those who develop joint pain and swelling often need a rheumatologist. Those who have issues with their kidneys will need a nephrologist.

Black Americans may also deal with unequal access to specialty care in rural areas and are consistently underrepresented in lupus clinical trials. When investigating the factors that lead to healthcare inequities for Black people living with lupus, researchers identified poor communication between healthcare providers and patients as a serious problem.

In this study, patients noted that they were dissatisfied with how their doctors communicated with them and found that they didn't listen to their complaints. These doctors also didn't effectively communicate with their patients about their symptoms, treatment, or how to manage the disease well. As a result, the Black Americans in this study were more likely to see their illness progress and have more emergency room visits.

Given that Black people can have differing symptoms from other ethnicities, some health professionals have suggested that they seek culturally competent care for better results. With this kind of care, the physicians will be trained to assess Black Americans on the specific symptoms they deal with as well as the potential complications. They will also be able to communicate effectively while understanding why Black people usually don't trust the medical community.

By exploring culturally competent care, you're likely to experience a better relationship with your doctors and have better quality of care.

To find a provider, Lupus Therapeutics, the clinical affiliate of the Lupus Research Alliance, has a helpful directory for the lupus community.

CHAPTER 4:

MANAGING LUPUS DAY-TO-DAY

TREATMENT OPTIONS

Lupus is a chronic disease, which means that it can't be cured. However, your doctor can prescribe different medications that can help manage your symptoms. **Anti-inflammatory drugs can be used to reduce pain, inflammation, and joint swelling.** Corticosteroids are an anti-inflammatory drug that can be used to reduce your immune system's attacks and soothe symptoms, including tenderness, pain, and swelling. However, corticosteroids have serious side effects and need to be used with caution. You will need to discuss with your doctors the risks and benefits.

Antimalarial drugs can help the immune dysregulation and treat inflammation, fatigue, skin rashes, and joint pain. You may also get anticoagulants because people with lupus have a higher risk of developing blood clots.

If your symptoms are moderate to severe, your doctor may go a step further and prescribe immunosuppressants. These drugs will suppress your immune system and stop it from attacking your healthy tissue. However, it has some side effects that you need to discuss with your doctor. Some common ones include being more prone to developing infections, having gastrointestinal issues like gastritis, peptic ulcers, and gastrointestinal bleeding, getting headaches.

It's important to note, though, that you're not limited to prescribed medication when dealing with lupus. Alternative and complementary treatments are meant to supplement your medical therapy, but can't replace it. While they can be helpful, **you shouldn't start anything new without talking to your doctor first.**

Some options that you can explore include yoga, meditation, and tai chi, as they may reduce your stress level. Managing your stress can help reduce your flares as well. Some studies also suggest that different types of touch therapy can help manage your symptoms. A few of these options are massage therapy, chiropractic therapy, and acupuncture.

Other aspects of alternative medicine can combine two things. For example, Traditional Chinese medicine can mix herbs with acupuncture or Tai chi. Other types of alternative medicine are homeopathy, naturopathy, and Ayurvedic medicine.

LIFESTYLE ADJUSTMENTS

Apart from exploring different forms of treatment, there are certain things you can change about your lifestyle to remain healthy with lupus. The first thing you should do is avoid the things that trigger lupus flares. For example, the **sun can trigger rashes and flares. It's a good idea to avoid the sun when possible.** If you can't avoid it, wear sunscreen and cover up with the appropriate clothing.

It's also essential to have a healthy diet and a healthy weight. While there's no set diet for lupus, doctors advise filling half of your plate with fresh fruits and vegetables. Whole grains like whole-wheat bread, whole-wheat pasta, oatmeal, and brown rice, as well as healthy proteins like lean meats, poultry, seafood, eggs, beans, and nuts, should complete your meal. Instead of foods with unhealthy fats, you should opt for healthy ones like nuts, fish, olive oil, and avocados.

You should also stay away from high-sugar foods, foods that are high in salt, and those that are heavily processed. If you have lupus nephritis, you may have other food restrictions that you need to pay attention to. This should be discussed with your doctor.

Regular exercise offers several benefits to people with lupus. It can strengthen your heart, bones, joints, and lungs while reducing inflammation in the body. If you're experiencing muscle stiffness, exercise can help loosen them. Exercise is also an effective mood regulator and stress management technique.

The key to exercising with lupus is finding what works best for you. **Doctors recommend activities like walking, swimming, bicycling, low-impact aerobics, specific kinds of yoga, Pilates, stretching, water-based routines, or using an elliptical exercise machine.**

On the other side of things, you also need to rest. People with lupus usually deal with periods of extreme fatigue so it's a good idea not to push being active over getting rest, as you may trigger a flare. A good bedtime routine and having a comfortable bedroom can go a long way to guaranteeing a good night's sleep.

One thing to avoid is cigarette smoking, as the chemicals in cigarettes can worsen your symptoms.

Finally, you need to reduce your stress as much as possible. High stress can not only worsen your lupus symptoms, but it can also increase the frequency of your flares. Some things you can do are avoid stressful people or situations, practice calming techniques like yoga or meditation, and sleep well.

TRACKING SYMPTOMS AND FLARES

Lupus symptoms can vary and worsen over time. Additionally, when you're having a flare, your symptoms can get worse or you can have new ones. **Some triggers that can lead to a flare are emotional stress, infections, colds or viral illnesses, exhaustion, severe exposure to ultraviolet rays, or an injury.**

Tracking changes in your symptoms and flares can help your doctor assess your medical regimen as they can see patterns. It may mean that your medication needs to be modified. **One of the most effective ways to track your symptoms is through a daily journal, as you can share it with your doctor.**

Some of the areas that you should track include changes in fatigue, joint pain, rashes, mouth sores fever, and brain fog. If you were exposed to potential triggers like sunlight, stress, or different medications, you should note that as well. When documenting your symptoms, you should note their severity, duration, how they limited your ability to carry out daily tasks, and location, if applicable.

You should always note if you've experienced any new symptoms. **Some potential symptoms are fatigue, joint pain, skin rashes, mouth ulcers, hair loss, headaches, unexplained fever, chest pain, changes in your urine, and changes in photosensitivity.**

To make tracking easier, the Lupus Foundation has a symptoms tracker that you can use. If you're looking for phone-friendly options, there are also apps that can help you.

CHAPTER 5:

EMOTIONAL AND MENTAL HEALTH

COPING WITH A CHRONIC ILLNESS

Living with lupus can negatively affect your mental health. **Doctors note that people with the condition can experience more frequent episodes of anxiety and depression.** That's why it's essential to consider psychotherapy as part of your treatment program.

Depression can lead to a lack of interest in activities that used to bring you joy, feeling hopeless, appetite changes, a lack of sleep, crying for no reason, having no energy for daily tasks, an inability to concentrate, indecisiveness, and intrusive thoughts of suicide.

If you're dealing with anxiety, you may be inexplicably nervous, have an increased heart rate, tremble without explanation, sweat, have changes in your body temperature, breathe faster than normal, and feel an unexplained sense of impending doom.

By seeking therapy you can get help for these symptoms. This doesn't necessarily mean that you'll be prescribed medication for it as this depends on the severity of your symptoms. However, your therapist and your doctor will assess whether or not you need drugs in addition to therapy.

Therapy for Black Girls is an excellent place to start when looking for Black therapists. You can also find **apps or online resources** that can help you manage your mental health while living with lupus.

FINDING SUPPORT

As with many chronic illnesses, **support from loved ones and those in a similar situation can be an enormous help while dealing with lupus.** Your family and friends can offer support in the form of listening to you and stepping in when you're not able to carry out your daily activities.

Support groups can be integral in not only talking about what you're going through but also in pointing you in the direction of great resources you can use. Since it's been documented that Black women don't usually get the level of care they need, it can be good to find out from others how they finally achieved what they were aiming for.

Additionally, support groups aren't just for people dealing with lupus. Caregivers, family members, partners, and friends can benefit from these groups as well. They will gain a better understanding of what to expect as you navigate your new life.

The Lupus Foundation offers a comprehensive list for those who are looking for support groups. The good thing about this list is that it not only includes groups for Black people with the disease but also groups that have other interests, like military personnel.

The Lupus Support Group for Women of Color is available nationwide, and this group's focus is on supporting and educating women of color about lupus. They also invite health experts to be a part of the conversation during monthly meetings. In this way, they aim to spread awareness about how lupus disproportionately affects Black women.

The Lupus Research Alliance and clinical affiliate Lupus Therapeutics offers resources for the lupus community – especially for those who might be interested or are currently participating in clinical trials for lupus therapies.

BUILDING RESILIENCE

Getting a diagnosis and starting treatment for lupus can be difficult for Black people. If you're getting ready to tackle that, you should know that you're far from alone. In the sea of women who have had to endure a lot to get the healthcare they need, it's good to highlight a couple who can inspire you.

It took **Kimberly Dansby** well over a decade to get to the point where she was diagnosed and getting consistent treatment. **In 2004, she started to lose her hair. Though she was only 22 at the time,** she attributed the hair loss to the stress of being a full-time student while also working full-time. She'd also just had her daughter, so she wasn't surprised that she was tired.

Within another few years, though, her symptoms worsened to the point of her having a permanent disability and being unable to work. During this time, **doctors had misdiagnosed her several times and her condition hadn't improved.** She was a little over 30 when she was finally diagnosed with lupus.

Unfortunately, being unemployed with a disability made it difficult for her to take her medication consistently, and she had at least three grand mal seizures in one year. It wasn't until late 2013 that she became eligible for Medicare and was finally able to afford her medication. **Her experience led her to grow the Purple Rose Foundation, which focuses on growing lupus awareness in the Black community.**

Nadine Kidd also has quite the story to tell when it comes to her lupus journey. She started having symptoms of lupus as early as third grade. **She recalls being misdiagnosed with allergies and migraines.** In one particularly disturbing case, she was dismissed from a hospital and described as a 'crack addict' who was only seeking painkillers despite her debilitating pain.

Kidd recounts experiencing mistreatment based on her race despite the aggressive nature of her condition. When she had her first major flare, she was left in the dark on a hospital gurney, where she eventually passed out from the pain. She was eventually discharged without a diagnosis and any discussion of her medical history. **The delay in treatment resulted in a brain hemorrhage, which resulted in a month-long stay in the ICU.**

Thankfully, through the advocacy of a good doctor, she was finally diagnosed with lupus at the age of 21. Though she is living well with the condition, the delay in diagnosis means that she has dealt with arthritic pain, fatigue, nausea, stroke, sepsis, stage 4 kidney disease, and more. Still, she continues to persevere and encourages Black women to advocate for themselves when they're not feeling well. **An early diagnosis is essential to avoid severe or permanent damage.**

CHAPTER 6:

ADVOCATING FOR EQUITY IN CARE

BREAKING THE BARRIERS

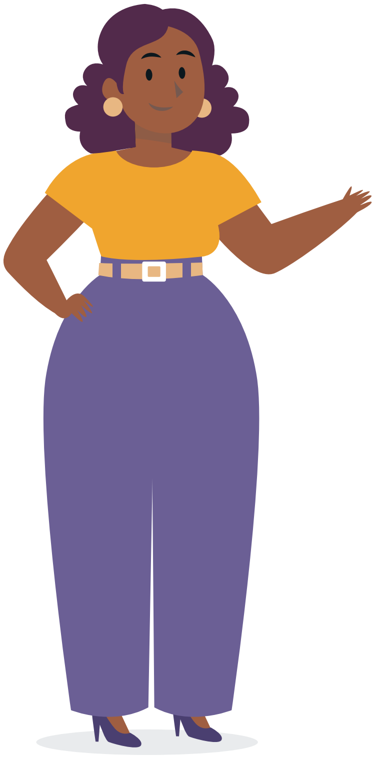
Though Black Americans have a higher risk of developing lupus, many of them aren't aware of it. They're also not sure about the symptoms of the illness and why they have to advocate for better healthcare. Fortunately, there are ways everyone can get involved with changing this.

You can seek out local Black organizations as well as influencers and persons who have personal experience with lupus. The aim would be to host educational events within your community where everyone would be able to share their stories and what everyone needs to know about how lupus affects the Black community.

Community events are also a good place to communicate culturally relevant information about how Black people can advocate for themselves in a medical setting to get the care they need.

You don't have to wait for a formal gathering to spread awareness about lupus, though. Social media is capable of getting the word out about anything. The Lupus Foundation has an excellent resource for crafting your message so you can be effective and consistent.

REPRESENTATION IN RESEARCH



Approximately 43% of the people who have SLE are Black Americans, but only 14% of the participants in lupus clinical trials are Black. When investigating the gap, the two main barriers identified were a lack of awareness of the benefits of clinical trials and the level of mistrust that Black people have for the medical community.

Being involved in clinical trials can be life-changing for Black Americans. While the participants get access to diagnostic and treatment advancements, that's not the only important factor. Clinical trials generate data that can influence further research. For example, doctors may realize that some medications aren't as effective for some ethnicities, especially Black people.

Some organizations ,like the American College of Rheumatology, have implemented programs such as the Training to Increase Minority Enrollment in Lupus Clinical Trials with Community Engagement (TIMELY) to increase the number of minorities in clinical trials, but more work needs to be done.

The Lupus Research Alliance and clinical affiliate Lupus Therapeutics are playing an important role in this space – engaging people living with lupus through every aspect of the clinical research continuum. From patient engagement programs and resources – the organization is working toward finding and developing breakthrough therapies and, ultimately, a cure.

You can play a role by educating people in your community about clinical trials and how to get access to them.

POLICY CHANGE

While learning to advocate for yourself is a good start, real change happens at a policy level. **Policies are what will drive the medical community to put processes in place to guarantee that Black Americans receive the same level of care as everyone else.**

Some of the ways the inequity can be addressed are educating doctors about the differences in lupus symptoms in Black people, identifying and addressing the inherent biases that still exist in the medical community, and allocating funding to ensure that Black people have access to diagnostic care.

To accomplish this, it's best to speak with your local political representative. If you have the community behind you, this can also help to gain some traction.

CHAPTER 7:

STORIES OF HOPE AND STRENGTH

LUPUS WARRIORS ACROSS THE BLACK COMMUNITY

Living with lupus can look different for everyone. While managing their symptoms, some people are living as well as they can while also working to raise awareness about the condition. One person who's doing that is **Tanya Taylor Johnson.**

Johnson was diagnosed at an early age, but her medical regimen didn't stop her autoimmune condition from damaging her kidneys. During an interview, she mentioned that her severe kidney damage led her to speak up about lupus. She wanted more people to know about how the illness can affect the kidneys.

While waiting for a kidney transplant, Johnson remains positive and undergoes dialysis three times a week to remain healthy.

Another Black American woman who's working to make a difference is Kaamilah Gilyard. Her road to getting a lupus diagnosis was a long and hard one, which led to prolonged illness and several stays in the hospital. Her experience has made her adamant about not only educating Black people about the importance of clinical trials but also participating in them.

She has participated in clinical trials that focused on the link between lupus and genetics and potential new treatments. Gilyard views her participation in clinical trials as an integral part of addressing the current healthcare disparities when it comes to Black Americans and lupus.

When speaking with the Lupus Research Alliance, she said, **"Lupus is not a black disease, but people who look like me are at greater risk and have a higher rate of its most severe forms.** If we don't feel obligated to support research for our community, then who is supposed to do it? And if we don't, how can we know if the drugs being tested will work for us?"

LESSONS LEARNED

Though Chastity Hart was diagnosed with lupus at 16, it took some time for doctors to get her symptoms under control. Even after starting treatment, she became paralyzed for a few months. As she slowly regained her ability to walk, she struggled with her mental health as well. Hart didn't let it keep her down.

In an interview, she noted, "I always felt like everything I was going through was temporary. I never looked at it as my forever," she says. "God gave me that kind of peace. So honestly, I never really worried. I'd be sad sometimes, but I never stayed in that space."

Cori Broadus was diagnosed with lupus at an even earlier age. At only six years old, she started a daily medical regimen that included as many as 12 pills. As she grew up, she focused on changing her lifestyle to remain healthy while living with lupus. Broadus emphasizes staying hydrated, eating healthily, and having a regular exercise routine.

However, she wants people to know that it's not a sudden change, telling an interviewer, "But I tell people all the time, it's a day-by-day process. Things are going to take time. Nothing is going to happen overnight."

CONCLUSION

KEY TAKEAWAYS

Lupus is a chronic condition that affects Black people more than other ethnicities. However, that doesn't mean you can't live a healthy life with it. The best thing you can do for yourself is to learn everything you can about lupus so you can recognize the symptoms as soon as they appear.

You should also learn how to communicate these symptoms to your doctor, as they may still be looking for typical representations that are more obvious in those with a lighter complexion. It can help to document what you're going through, as this may lead to an earlier diagnosis.

If you're diagnosed with the condition, don't forget the importance of having a support system. This can be composed of your loved ones, medical professionals, and your community.

CALL TO ACTION

Now that you know more about lupus, you can help others by spreading the word. You can share this eBook as well as other resources that you've found. Though other factors negatively impact Black Americans being diagnosed with lupus, not being aware of the illness is a critical one.

Teaching more Black people about lupus and the disparities in healthcare they may face can also help them to advocate for change. When you work together, you can form community organizations or join those who are working towards changes in medical policies.

Overall, though, you can use what you know to make changes in your life to ensure that you remain healthy with or without lupus.

APPENDIX

RESOURCES AND CONTACTS

The Lupus Research Alliance

Lupus Therapeutics

Lupus Foundation of America

The Foundation for Black Women's Wellness

Lupus and Allied Diseases Association

Charla de Lupus (Lupus Chat)®

FURTHER READING

1. African Americans and Lupus - https://www.lupus.org/s3fs-public/Doc%20-%20PDF/Ohio/African%20Americans%20and%20Lupus.pdf
2. What African Americans Need to Know About Lupus - https://www.healthline.com/health/lupus/lupus-symptoms-african-american#lupus-rash-on-black-skin
3. What to know about lupus rash on African American skin - https://www.medicalnewstoday.com/articles/african-american-lupus-rash
4. Lupus Facts and Statistics - https://www.lupus.org/resources/lupus-facts-and-statistics
5. Lupus Diagnosis and Treatment - https://www.mayoclinic.org/diseases-conditions/lupus/diagnosis-treatment/drc-20365790
6. Lupus: Tips for Everyday Living - https://www.webmd.com/lupus/lupus-tips-everyday-living

7. Treating and managing lupus and preventing flares - https://www.medicalnewstoday.com/articles/323665

8. Eating Healthy When You Have Lupus - https://www.lupus.org/resources/diet-and-nutrition-with-lupus

9. Complementary and Alternative Medicine for Lupus - https://www.lupus.org/resources/are-there-complementary-and-alternative-medicine-therapies-for-lupus

10. Find Clinical Trials - https://www.lupus.org/research/find-clinical-trials

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