

Marsha Henderson

Sarcoidosis



I was diagnosed with pulmonary sarcoidosis in 1995 and then neuro-sarcoidosis in 2002 while working as an emergency medical technician in Washington, D.C. Since my diagnosis, I have faced incredible physical changes and emotional challenges that have interfered with my life and the lives of my family, friends, and colleagues.

In the beginning, I tried to act as normally as I could, continuing to work and meet my social obligations. But it was just an act because the reality was that I felt far from normal. I was struggling to breathe and dealing with extreme fatigue. It was draining to be physically limited in all my daily activities and difficult trying to explain to others what I was going through. As hard as it was to manage my physical symptoms, I found it even harder to cope with the impact sarcoidosis had on my emotions.

Living with sarcoidosis has had a significant impact on my mental and emotional well-being. The constant battle has led me to feel anxious and depressed. Many times, social isolation has rendered me unable to participate in activities or spend time with family or friends. This always leaves me feeling a profound sense of loneliness. I feel a sense of loss or grief for the life I had before my illness. I practice self-care techniques such as meditation and breathing exercises to help improve my state of mind. My biggest hurdle has always been dealing with the uncertainty and unpredictability of my condition. I must constantly manage my illness, follow treatment plans, and make lifestyle adjustments. All that leaves me feeling utterly overwhelmed - even angry and resentful.

My family and friends have experienced a range of emotions themselves, including worry, stress, and even guilt. Their constant concern for my well-being has often left them emotionally drained. Many of them have taken on unassigned caregiving responsibilities for my children, which can be both physically and emotionally demanding. I realize that I may be the one diagnosed with a respiratory illness, but what I am going

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through also impacts them. My friends have tried their best to balance my health issues with their own obligations to work and other commitments, although a few were not successful at it. Sadly, these friendships did not endure because of a lack of understanding about my illness.

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Respiratory illness has also impacted my livelihood. It became very challenging trying to ask for special accommodations, time off, or workload adjustments due to sarcoidosis. My physical limitations and health-related absences affected my productivity at work, which ultimately forced me to retire early and go on disability. I had to leave a job that I loved. I missed the support and friendship of my coworkers. I felt profoundly sad and isolated, not to mention worried about the financial burden of being unable to afford as much as I used to. The loss of income, coupled with increased medical expenses related to hospital visits, medications, and tests, caused major financial instability.

Taking care of my mental and emotional well-being has been crucial for me. My family and I see a therapist who specializes in chronic illness. She helps us to navigate emotional challenges and develop coping strategies. Plus, she provides a safe space for us to express our fears and concerns. Also, I connect with others who are facing the same challenges as I am. These groups provide me and my family with a sense of belonging, understanding, and encouragement, as well as help to alleviate my feelings of isolation.

After years of many doctor appointments and searching for answers, I connected with the Foundation for Sarcoidosis Research (FSR). The FSR is an international patient advocacy organization dedicated to finding a cure and better treatments. The FSR was a breath of fresh air, and I am grateful that the American Thoracic Society has partnered with them to help advance the health of those impacted by sarcoidosis and respiratory diseases. Currently, I'm an FSR Patient Advocate.

I encourage anyone suffering from respiratory illness to get in touch with a patient advocacy organization. These organizations are dedicated to supporting individuals with specific illnesses or conditions and provide informational resources, connect individuals with support groups, and advocate for patient rights. Some even offer financial assistance programs. But what I find most helpful is the sense of community they provide. Through my involvement, I am reminded that I am not alone in this journey.

Whether it is dealing with physical challenges, emotional struggles, or financial burdens, there are resources, support systems, and people who genuinely care about the well-being of patients. I would encourage anyone suffering from sarcoidosis or any respiratory illness to reach out for help when they need it. Building a dedicated support network can make a world of difference. You are stronger than you think, and there is always hope for better days ahead. It is that hope that anchors my heart. ●

Sarcoidosis

Sarcoidosis is a disease of unknown cause in which inflammatory cells clump together and form tiny lumps of cells in various organs and tissues of the body. Sarcoidosis most often affects the lungs and its hilar lymph nodes but can also involve other areas of the body including the eyes, skin, sinuses, liver, kidneys, brain and heart.

- When sarcoidosis affects the lungs (pulmonary sarcoidosis), the disease can reduce the amount of air the lungs can hold and cause abnormal stiffness, called “restriction,” of the lungs. This results in breathing problems that can interfere with daily activities.
- Since sarcoidosis can affect one or more parts of the body, the signs and symptoms depend on the tissue/organs involved. Some people with the disease do not have any symptoms and it may be noticed by chance when they are being seen for other problems. For other people it may be hard to diagnose because the symptoms they have are not very specific. But certain clinical features such as the erythema nodosum, rash or eye findings may lead a healthcare provider to suspect sarcoidosis.



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