Katherine Anne Lewis

PULMONARY ARTERIAL HYPERTENSION

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In 2009 I weighed 293 pounds, did not exercise, thought six hours of sleep was a good night's rest, and shouldered the stress of being the director of student services for a large school system. For most of my adult life I struggled with "bronchial problems," but the frequency of my breathing difficulties and shortness of breath increased. I could not walk from my office to the opposite end of the building without stopping to catch my breath, and climbing stairs was virtually impossible. Then my ankles started swelling, and I was constantly fatigued. My son and my sister, two people who know me best, pressed me to see my physician.

I knew that my primary care physician would once again say that I needed to lose weight, exercise, and sleep more. But that was not the case this time. She ordered tests. I still believed that nothing much was wrong.

Many tests, appointments, and doctors later I was diagnosed with pulmonary arterial hypertension, prescribed one medication, and told to lose weight. I returned home from that appointment and read everything I could find about PAH. Articles suggested that I should adjust to my "new normal," would continue to worsen, and had only two to four years to live.

Subsequent appointments taught me that most of what I had read was outdated. I don't give up easily, and I began to see myself as a partner in my health care, willing to do whatever I could to maintain quality of life—and maintain life itself.

The nurse coordinator and pulmonologist specializing in PH recommended a pulmonary rehab study through the NIH. For 10 weeks I drove to the NIH during rush hour and worked with a physical therapist and exercise specialist, walking on a treadmill and participating in educational sessions. Before the study ended I joined a local gym; I was not going to sacrifice the progress I had made.

I have exercised at the gym regularly, and I now also work with a fitness coach who specializes in clients with lung diseases.

PULMONARY ARTERIAL HYPERTENSION

The pressure that the right side of your heart is pumping against is called your pulmonary pressure. When this pressure is too high, it is called pulmonary hypertension (PH).

Pulmonary Arterial Hypertension (PAH) used to be called "primary pulmonary hypertension". PAH occurs when the blood vessels in the lung are directly diseased (unlike the other forms of PH where the increased pressure is due to another reason like chronic lung or heart disease) and become thick and narrow. The pressure on the right side of your heart increases as it tries to pump blood through these narrow blood vessels. In PAH the pressure that the right side of your heart is pumping against is usually a much higher pressure than in patients who have PH from other causes.

Learn more: ATS Patient Education Series. "Pulmonary Arterial Hypertension" New York, NY. www.thoracic.org/patients/patient-resources/resources/pulmonary-hypertension.pdf

When I started having GI difficulties, I learned of a rheumatologist, who understood PH and might be able to help. She explained that I also had limited systemic scleroderma, helped to control my esophageal and GI issues, and continues to monitor my condition.

I'm participating in an NIH natural history study that collects data about individuals with PH. I'm hopeful it may lead to the further development of therapies, or even a cure.

Currently, I weigh 136 pounds. I feel strong, I continue to take my medications, I eat wisely, exercise frequently, and am not afraid to take on life's challenges. In the past three years I have traveled internationally, my portable oxygen concentrator in tow.

PH medicines have changed along the way. I am grateful for the work that has resulted in my new medications, and for my health care team who stays current and helps design solutions that work best for my body.

Katherine Anne Lewis was a patient speaker at the ATS 2017 International Conference in Washington, D.C.