"How could sleep or lack of quality sleep be the reason why my heart wasn’t working properly? This scared me enough to get more studies done."
In 1996 soon after I delivered my third daughter I started having strange symptoms. Shortness of breath, palpitations, and extreme exhaustion plagued me day and night.

For three years while I was misdiagnosed I kept being told: it was all in my head, I was being too lazy, and that I should stop playing around. Then I was told I have a terminal progressive and very rare condition called primary pulmonary hypertension. I was given two years to live.

Soon after, I was sent to a specialist for evaluation in a sleep study. What a bizarre test! Tubing everywhere, on my head and face, with straps around my chest, wires taped down to me all over. When they said “Go to sleep!” it was almost impossible to get comfortable! Yet after some time of praying for sleep I was actually able to. Moments later, it felt, I was woken up.

Eventually, the technician said that I had severe obstructive sleep apnea. Finally, my condition had a name, it was not all in my head!

I don’t remember the number of episodes I had per hour, but I remember a feeling of shock. I was asked to return for a second study to be fitted for a CPAP mask. I made the appointment, but I never went.

I couldn’t imagine lying in bed next to my spouse with a contraption over my face. I thought, I was already attached to a pump delivering sodium, a life-saving medication for my pulmonary hypertension that had to be surgically connected with the very tip of the catheter inside my heart. I felt ugly, unlovable, and alien! There was no way I was going to add something else to cover my face.

Ten years later in 2008, I went through a painful divorce that I thought I’d never live through. I moved in with my sister in Washington, D.C., and I started seeing a different doctor at Johns Hopkins Hospital.

After performing a right heart catheterization on me, my doctor informed me that my

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Obstructive sleep apnea (OSA) is a common problem that affects a person’s breathing during sleep. A person with OSA has times during sleep in which air cannot flow normally into the lungs. The block in airflow (obstruction) is usually caused by the collapse of the soft tissues in the back of the throat (upper airway) and tongue during sleep. Apnea means not breathing. In OSA, you may stop breathing for short periods of time. Even when you are trying to breathe, there may be little or no airflow into the lungs.

Common symptoms you may have during sleep

- Snoring that is usually loud and bothers other people trying to sleep near you.
- Gasping or choking sounds
- Breathing pauses
- Sudden or jerky body movements
- Restless tossing and turning
- Frequent awakenings from sleep

cardiac output was extremely low. He believed my sleep apnea, which had worsened over the years, was the cause.

Again, I was shocked. How could sleep or lack of quality sleep be the reason why my heart wasn’t working properly? This scared me enough to get more studies done. Soon, a rep from a respiratory therapy company arrived at my house to drop off my new CPAP machine, show me how to use it, and how to wear the mask.

I wore the mask every night, but I’d wake up to go to the bathroom and find the mask either on the floor or on the bed beside me. I must have yanked it off in my sleep. This happened without fail for nearly three weeks. Then one day I woke up wearing the mask. Now I have been wearing the CPAP mask during the night, as well as any time I need a nap, for nearly 10 years!

Alex Flipse was a patient speaker at the ATS 2017 International Conference in Washington, D.C.