

Kathy Page

Sleep Apnea

Nighttime was never relaxing for me. When others were getting a good night's rest, I was struggling with restless leg syndrome. Several years ago, a doctor suggested that it might be stress and hormones preventing me from getting good sleep. Following that, I made several lifestyle changes, but to no avail. I was tired and emotionally drained from not being able to get a decent night's rest, so I decided to participate in a clinical sleep study. I wanted to see if anything could be done for my restless leg syndrome.

Results are usually given a week after the participant concludes the study, but in my case, the doctor was ready and waiting to give me the results right away. It was sleep apnea. I was in total shock – and so began my journey with this illness. I was advised to begin using a continuous positive airway pressure (CPAP) machine, which I felt anxious about. I had seen

pictures of people strapped to these contraptions and had heard stories from those who had used them. My first thought was, "Nope – this is absolutely not happening." I was scared and, in some sense, ashamed.

I didn't want my husband to see me wearing the mask. I didn't want family or friends to know I needed to use the machine. I tried to reason myself out of using it, thinking that maybe I could live with sleep apnea after all. But it didn't take me long to realize the folly in that. Not getting good sleep can affect your blood pressure, heart, lungs, brain, as well as how you feel about yourself. Not only are you physically tired, but it can leave you emotionally drained, as well. Sleep is an essential function that allows your body and mind to recharge. Good rest enables your immune system to function optimally, to stave off disease and keep you healthy.

Despite my initial misgivings, I started using the CPAP machine. I had no other choice. Regardless of whether I wanted to use it or not, I had to use it to get better. I've now gotten used to wearing it and in fact don't sleep well without it. But I still dislike wearing it. It's bulky and uncomfortable. It makes rude noises when it leaks. And then there are the strap marks it leaves on my face, which I've had to endure strangers commenting on.

There's a social stigma to having to use a CPAP machine: it flags to others that there is something "wrong" with you. I remember being quite embarrassed whenever I had to go through an airport and unpack the machine.

It would invite stares and whispers from onlookers, and inevitably I'd feel the stress of having to explain my condition to TSA agents. Fortunately, I'm TSA pre-certified now and don't have to take it out of the bag anymore, but I empathize with people who must experience this.

It's why I say I have a love-hate relationship with my machine: I rely on it for adequate rest, but I hate using it otherwise. What keeps me positive is just recognizing that there are a lot of people out there like me and that there are scores more who have it worse off.

Over the last few years, I've gotten involved with a group called ASAP, the Alliance of Sleep Apnea Partners. We started out just as a grassroots organization, a group of people that have sleep apnea and wanted to share information with each other and others who may suffer from the condition. We've grown into a nonprofit with a virtual community of over 20,000 patients.

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Before my diagnosis, I had no idea so many people had this illness. As a past president of ASAP's board of directors, I've now had the opportunity to guide the organization in its mission to empower patients with information and opportunities to connect. We now have an executive director and a social media lead, which has helped our cause tremendously and enabled us to do more work in the advocacy space.

Getting involved with ASAP has been just as beneficial for me as it has been for the organization. It's given me a sense of empowerment over this illness and enabled me to help others through their own feelings of being helpless and overwhelmed. I encourage anyone who may be going through this to get involved and realize that they are far from alone.

Sleep Apnea

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. There are many clues that can make one suspect that you may have OSA. You may not be aware that you have OSA, but these symptoms may be more obvious to a spouse, other family member, or close friend.

Common symptoms you may have during sleep:

- Snoring that is usually loud and bothers other people trying to sleep near you. Snoring can come and go through the night.
- Gasping or choking sounds.
- Breathing pauses observed by someone watching you sleep. Sudden or jerky body movements.
- Restless tossing and turning.
- Frequent awakenings from sleep.

