“I still struggle with being tired and losing weight. But I am not grumpy like my dad was, and I’m negotiating life pretty well.”
Obstructive Sleep Apnea runs in my family. My father, sister, nephew, two teenage sons, and I have had it.

As a child, I was the spitting image of my father: foggy headed and a late bed wetter. Each morning, I heard him snore, but I didn't pay attention because I had to get myself focused. My twin sister was always chipper, but I felt like I had a perpetual hangover. I got Ds and Cs on my report card. Little did I know that OSA was causing my cognitive dysfunction and bedwetting.

During my early teens, my father developed Gastroesophageal reflux disease and then asthma. He took a lot of medications and became a huge grouch. As for me, I could not sit still in orchestra with what was most likely attention deficit hyperactivity disorder.

When my tonsils and adenoids were removed, I got smart, filled out physically, and began earning As and Bs—I could breathe again. My ADHD subsided, and I later finished two engineering degrees at Stanford University.

My father, on the other hand, was not doing so well, and snored like a freight train. He had an emergency triple bypass, and his snoring became epic, which made him persona non grata on hunting and ski trips. My mother was psychotic from lack of sleep, and she dreamt of killing my father—but not often, because she could not sleep. He then developed diabetes, prostate cancer, and ultimately passed away from pancreatic cancer, likely a complication from diabetes though he ate healthful foods.

I did well in my Silicon Valley career, but in my 40s, I began to suffer from lack of concentration, sleepiness, and hyperactive thoughts—my OSA had returned.

After a sleep study, I was diagnosed with mild apnea, and I tried oral appliances. Then I had major surgery through which my tongue was moved forward (the logic being

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it must need more room). The surgery was not a success; I learned what it was to be among the 30 percent with no cure. I struggled again until I met the founder of Resmed, who signed me up for a Continuous Positive Airway Pressure (CPAP) machine, and I have been a faithful user ever since.

I am not convinced CPAP therapy is perfect. Who wants to be tied to the electrical grid every night? I still struggle with being tired and losing weight. But I am not grumpy like my dad was, and I’m negotiating life pretty well.

As the board chair of the American Sleep Apnea Association, I work every day to help others find treatment. I am lucky because I’ve been treated, but 35 million Americans are going down the same path as my father. There has to be a better way.

So, how do we stomp out OSA and become apnea avengers and rid ourselves of this evil with asymmetrical force? The next big research idea is the Patient-Centered Outcomes Research Institute, which funds research that is “guided by patients, caregivers and the broader health care community.” Many with OSA have become experts with knowledge to share, like myself, and through this we can combine 50,000 OSA patient-experts and improve our collective outcomes via patient-informed research.

Like many issues and diseases, it takes generations to sort them out and improve. My father suffered. I suffered less. I am hoping my nephew’s son will avoid any of it.

*Will Headaphol was a patient speaker at the ATS 2014 International Conference in San Diego.*