I heard the whooshing sound early one morning, looked beside me and asked my husband if he heard it, too. He didn’t. “It pulses in and out to the pace of my heartbeat,” I said. “Like blood through my veins.”

Two weeks later, the sound remained and my anxiety increased. Apprehensively, I made appointments with doctors and hoped it would just go away on its own.

The whooshing soon had debilitating effects on my work, sleep, relationships, and my overall physical and psychological health. Isolation and depression ensued. By the time I saw my first doctor, an ENT specialist, I was terrified.

“You have tinnitus. There’s no cure, and you have to live with it,” he said, before even a single diagnostic test.

“Excuse me? Live with this? Are you kidding?”

But wait, tinnitus is often described as a constant buzzing or ringing of the ears. That doesn’t describe the sound I hear. Nonetheless, my conversation with that doctor quickly ended.

He was correct about one thing: there is no cure for tinnitus. But, as it turned out, his diagnosis was not accurate and, as I would learn later, he was terribly wrong to end the inquiry there.

That’s because I have pulsatile tinnitus, a form of tinnitus that is distinguishable from the more common, ‘regular’ tinnitus.

Described as ‘the perception of a rhythmical noise that is synchronous with the patient’s heartbeat,’ pulsatile tinnitus can be a whooshing, clicking, buzzing, or screeching sound. Whatever its type, it’s a constant sound that fluctuates in and out. The list of possible causes is long and crosses many medical specialties, which often complicates proper diagnosis and treatment. While unlikely, some causes are potentially dangerous when left untreated.

According to several medical institutions, pulsatile tinnitus affects only 3% of tinnitus sufferers. A small fraction, unless you consider there are tens of millions of tinnitus sufferers worldwide.

So why didn’t my doctor recognise my pulsatile tinnitus symptoms?

Unfortunately, many doctors aren’t trained to recognise the difference between pulsatile tinnitus and regular tinnitus. A simple online search for “I hear my heartbeat,” reveals that men and women of all ages and sizes with pulsatile symptoms experience similar barriers to answers, often before they know their symptoms have a name.

In 2009, rather impulsively, I started whooshers.com - an online forum for pulsatile tinnitus sufferers. I compiled medical journal articles and news stories that proved what I’d discovered: pulsatile tinnitus is real and should not be treated like regular tinnitus.

The response has been overwhelming. Patients, doctors and even reporters interested in pulsatile tinnitus, have found the site. While whooshers.com is not a medical site (I specifically discourage self-diagnosis), visitors are encouraged to share their stories, even anonymously. Our Facebook and Twitter pages grow in membership every day.

The entire tinnitus community may be interested to know that there are pulsatile tinnitus patients who have been medically treated and relieved of the whooshing noise and the underlying causes.

Perhaps our growing community may provide some incentive for doctors to further explore pulsatile tinnitus. At the very least, I hope it encourages more doctors to recognise pulsatile tinnitus symptoms so that more of us can be diagnosed properly and treated promptly.

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The website is www.whooshers.com