

Joe Anderson  
Feature Writing  
5.2.14

## Searching for Silence

The familiar wintergreen scent that accompanies a fresh piece of gum signals the horrors that will soon follow. Every tantalizing second seems to last an eternity as the aluminum wrapper is slipped off of the everlasting mint and it is raised slowly towards the mouth. Once inside, the molars will pound it continuously into a soft ball, and each bite will be more sickening than the last. “For most people gum is a comfort food,” explains 24-year-old Nick Woods, “but for me it is torture.”

The sound of gum triggers a bodily response in Woods that is far more extreme than simple annoyance. With each bite his heart rate will increase and his body temperature will rise— symptoms most commonly ascribed to an anxiety attack. Although most people are able to distract themselves with other sounds or activities, Woods is different: the mashing of the gum will soon become the only sound he can focus on and, unable to escape the miserable experience, he becomes trapped, a prisoner in his own mind.

Woods suffers from a little known mental disorder known as Misophonia, which literally means ‘the hatred of sounds.’ Sufferers of Misophonia, (sometimes referred to as misophones) experience extreme fight or flight reactions to particular trigger sounds. A few of Woods’ common triggers include chewing, whistling, heavy breathing, sniffing, and snoring, but sometimes even specific voices and tones can become a problem. Though these sounds are simple annoyances for many, misophones are particularly perturbed and struggle to separate the troublesome disorder from their own personal lives.

Because the condition is not well known, many people suffer for years before discovering that their pain is caused by a real medical condition. Woods struggled to explain to his friends and family that what he was experiencing was more than mere annoyance. “They thought that I was overreacting and after awhile I started to believe them,” Woods states, explaining the disconnect between victims and family. This emotional distress is furthered by the invisibility of Misophonia, as people tend to write off disorders they can not see without being able to understand the full psychological effects.

Emlyn Altman has also been suffering from Misophonia for years. “I thought I was just sensitive,” she explained, adding that she did not know she was suffering from a legitimate medical disorder until she was diagnosed over three decades later. Now 44, Altman finally knows better. “Who would have dreamed that annoyance of simple sounds could be a medical issue?”

“With this type of condition, I feel like I am alone with my suffering and often say to myself, why doesn’t anyone else feel this way?” Altman said.

“When I kept my trigger discomfort to myself, it was like struggling in silence, for silence.”

## Sounds and Senses

Dinner tables are torture chambers and the traditional roast beef meal becomes an instrument of terror. The meat is tough, which means extra chewing— a nightmare for misophones. Unfortunately, even if you manage to block the sounds, it does not mean your suffering will end.

This is because the term Misophonia does not accurately represent the disorder that it attempts to describe. The prefix *miso* comes from the Greek word for hate or dislike while the term *phon* or *phono* means sound or voice. When combined, the term Misophonia literally means the hatred or dislike of sounds. However, Altman explains that her suffering is not limited to noise, she experiences visual and tactile triggers as well.

This is one of the reasons that gum is a common trigger for misophones. In addition to the painful sounds of chewing, the repetitive motion of the jaw moving up and down becomes nearly impossible to ignore. “Planes are the worst,” Woods explains, “everyone is chewing gum so I always wear headphones but then I have to keep my eyes closed because I still see everyone chewing around me.”

In addition to visual triggers, Altman has had problems with her tactile senses (sense of touch) since she was a young girl. For her, the smooth feel of silk or the texture of pantyhose can become triggers that are nearly impossible to touch. “Sometimes I have to slather on lots of hand lotion just to get dressed because I don’t like the feeling of some fabrics,” Altman states.

The term Misophonia was coined in 2001, attempting to describe the most recognizable symptom of the recently discovered disorder. Unfortunately, the name is misleading and forces misophones to identify with a disorder, which by definition does not describe the full array of symptoms they experience. This further complicates a disorder that is already difficult for most to understand and leaves misophones feeling even more helpless.

## Silent Suffering

Altman first began experiencing auditory triggers in her pre-teen years. The loss of her parents became a catalyst for many life changes, including a move to New York City to live with her aunt and uncle. Though Misophonia had already begun to affect her life, moving to the noisy and bustling city exposed her to many more triggers that were previously non-existent in her life.

The most prominent of her early triggers came from her uncle. He had sinus problems and his nose was always stuffed, forcing him to eat with his mouth open and resulting in agonizing triggers for Altman. “There were times that he would be chewing or slurping and it would drive me crazy,” she said. “I was so miserable at the dinner table that I couldn’t wait to bolt or go to my room.” Altman’s Misophonia sometimes took a toll on her home life, creating a barrier between her and her family at a time when she so desperately needed them.

Woods agrees that mealtimes provide intolerable triggers for misophones. “Chewing sounds are some of my worst triggers and the thing about meals is that you can’t leave and you can’t stop the sounds. My parents wouldn’t let me leave dinner early because they thought it was rude.” These social norms and politeness requirements can put misophones in a painful position, forcing them to stay in situations that they physically cannot stand.

Altman was so visibly distraught during mealtimes that her aunt began to notice and did her best to try and help. “She wound up being my best friend, I would tell her something was really bothering me and she understood.” Altman said. Unfortunately, most people are not as sympathetic as Altman’s aunt. Woods said, “When I would try and tell my family and friends that something they were doing was bothering me, they thought that I was overreacting. They don’t understand that what is happening to me is different than just annoyance.”

Because the disorder is difficult to understand, it is often interpreted as an overreaction. It is easy for people to sympathize with someone who suffers from a physical illness because the problem is clear and visible. However, Misophonia is an invisible illness, meaning that even though those afflicted with it may experience great pain, their suffering is not visible to the general population.

A combination of disbelief and humiliation from friends, family and peers causes many misophones to stop talking about their experiences. “Sometimes when I would try and tell people they would start chewing really loudly to see if it bothered me,” Woods said.

Other than her aunt, Altman kept her Misophonia to herself for most of her life. “I was not popular in school. I never talked to my friends about it. No one else seemed to be bothered. I never even said anything to doctors because I never thought my sensitivities were a medical problem.” Misophones are placed in an uncomfortable position, suffering silently from a disorder that no one else seems to understand while simultaneously attempting to avoid the noises and triggers they experience everyday.

## **Searching for Silence**

One of the primary symptoms of Misophonia is the intense fight or flight reaction. Mark Eagleton is a 40-year-old resident of Woodland CA, he is married, has three kids and has been suffering from Misophonia since he was nine years old. He explains that his reaction is always to flee, “I have never acted out violently, and I can’t imagine ever

doing so, but I do need to remove myself from the situation immediately if trigger sounds are present.”

Though there are some people who act out violently, Woods believes that the majority of sufferers choose to avoid or flee trigger sounds whenever possible. People with Misophonia spend much of their lives learning how to avoid sounds and situations that they know will be dangerous for them.

Eagleton works in a small office where trigger sounds are nearly impossible to avoid, especially because his coworkers will often eat and snack at their desks. “I wear headphones and listen to music. I try to keep the headphones off as much as I can, but I end up wearing them most of the day. When headphones aren’t an option, I excuse myself and leave.”

Altman keeps her hair long specifically so that she can use it to avoid visual triggers. “I haven’t cut my hair short in two or three decades and I use my long hair as blinders for my peripheral vision. I will sweep my hair to block the view. I may look ridiculous, but it helps.”

Woods explains that when triggers become really bad he will do just about anything to avoid them. “The strangest thing I ever did was probably when I was in college. There was this girl in one of my classes who was always chewing gum really loudly and so I started stealing her gum when she wasn’t looking.”

Altman works as an architectural designer and feels lucky that she works at a job where using headphones is common. “I found a pair that prevents me from hearing anything in my surrounding environment. I’ve had people two feet away try to talk to me and I’m oblivious.”

Unfortunately not all situations are as easy to deal with. Places like church, movies, and conferences, where a large number of people congregate close together, are inevitably filled with trigger sounds. Altman explained that the key to these types of events is to be proactive, “If I’m at a conference, I try to get to a seminar early so I can get a prime spot. Once I even switched seats four times in a one hour lecture to get away from triggers, you do what you gotta do.”

Misophones will do just about anything to avoid the horrendous triggers that they experience every day, but Altman furthers that, for her, these methods are secondary to the only true way to stop the suffering– to flee.

Fleeing from triggers is difficult in public, but becomes even more problematic at home. “If I have to leave the room,” Eagleton said, “My wife will get self conscious and try to lighten the mood by joking about trigger sounds. Meanwhile, I’m in the other room suffering from crippling anxiety and not laughing at her jokes.”

Avoiding trigger sounds made by strangers is far easier than avoiding sounds made by close friends or significant others because there is not as much to lose. Woods said, “Even when I tell people about it, they still think I’m mad at them if I have to leave or they think they did something wrong.”

This is especially problematic because Woods explains that trigger sounds are generally far worse for people that he is close with. With this disorder there seems to be a correlation between the amount of time you spend with someone and the number of sounds that trigger you. Woods said, “It’s the worst with my family, they are almost impossible to be around. I don’t always keep friends for very long because eventually I can’t stand to be around them.”

When I asked to speak with Eagleton he requested that our conversation take place over e-mail, because he knows that phone conversations often yield trigger sounds. This is just one of many ways that Misophonia has become a part of his daily life. Eagleton said, “Because I have been living with this condition for most of my life, I don’t think of it like changing my lifestyle. It is the only lifestyle I have ever known.”

## **Finding Support**

There is currently no known cure for Misophonia, and very little research has been done to help find one. This is largely because Misophonia is still a relatively new disorder (the term ‘Misophonia’ was coined back in 2001) and is still largely unknown among both the medical community and the general public. Altman said, “it’s about supply and demand—very few people are aware of the condition, including sufferers, doctors, and researchers. As such, there are very few research studies being conducted to determine what it is, what causes it, and how to treat it.”

Altman is passionate about helping to find a cure, so much so that she paid her way to London earlier this year to participate in one of the only extensive Misophonia studies to date. The goal of the study was to discover how the brain reacts while experiencing trigger sounds. Altman was placed in a functional MRI (fMRI) machine and exposed to trigger sounds at 2-3 second intervals. Though the experience was stressful and even torturous at times, she fought through it with the hope that this research would be one step closer to the cure.

The results of the study will probably not be released for another year but in the meantime Altman continues to pursue her own methods of activism. When she first learned about the mental disorder three years ago she started a website and blog titled SenseHaven.com. Though initially a venue to document her experiences and provide a central resource of information about Misophonia, SenseHaven has become an important outlet to help her connect with other sufferers and raise awareness of the disorder.

Since the site was launched she has had over 37,000 unique visitors and people have reached out to her from the UK, Sweden, India, France, Belgium and Argentina. “As

much as I was nervous about putting something together and never having done something like this, I was like, wow, people are looking for this. I'm able to help people."

Woods explains that online communities like SenseHaven.com are some of the only places that people with Misophonia can go to for support. "Sometimes I read blogs online just so that I feel like I'm not alone. It's nice to know that other people feel the same way I do," Woods said.

Altman has a lot of experience in computer work and she uses a programming metaphor to explain why the research has not happened and how it can continue. "Programmers are not the end users. They don't always know what the end users need. Unless the programmer gets feedback from the end user that there is a need for a certain function, it is never going to happen. That's what I feel about research. I don't think doctors and researchers understand how much of a need there is for Misophonia research."