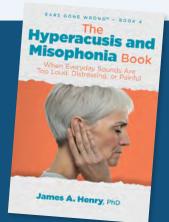
Breaking the Sound Barrier A Comprehensive and Accessible Resource on Sound Hypersensitivity Disorders



Title: The Hyperacusis and Misophonia Book: When Everyday Sounds Are Too Loud, Distressing, or Painful

Author: James A. Henry, PhD Publisher: Ears Gone Wrong, LLC Number of pages: 297 Hardback ISBN: 978-1-962629-09-6 Paperback ISBN: 978-1-962629-10-2 Ebook ISBN: 978-1-962629-11-9

New support group

ATA is pleased to announce that Dr. James A. Henry is leading the recently launched Hyperacusis and Other Sound Disorders Discussion Group. The group meets monthly and is run with the assistance of ATA volunteers Trudy Jacobson and David Treworgy. For more information, email trudyfromtucson@gmail.com or see ATA's support group listing webpage at https://www.ata. org/your-support-network/find-asupport-group/ By Kelly N. Jahn, AuD, PhD

Between 0.2 and 17.2 percent of the

general population is hypersensitive to sound.¹ Many of these individuals experience debilitating psychosocial consequences, including mental health challenges and social isolation.² Despite the high prevalence of sound hypersensitivity and its negative impact on quality of life, we do not know why some people have trouble tolerating sound, nor do we have broadly effective management solutions.

One of the primary reasons that we have many unanswered questions about sound hypersensitivity is that scientists and healthcare professionals do not widely agree on how to define the condition. Hyperacusis is often used as an umbrella term to refer to a reduced tolerance to ordinary sounds that do not bother most people.³ These broad definitions overlook the fact that "reduced tolerance to sounds" can manifest in many ways and that it can impact one's quality of life to varying degrees. In 2014, Dr. Richard Tyler and colleagues described four subtypes of hyperacusis that acknowledge the existence of multiple symptoms, including loudness intolerance, pain, annoyance, and fear.⁴ Still, scientists and clinicians continue to use myriad terms and definitions to describe sound hypersensitivity symptoms.

This lack of consensus has led to widespread confusion among scientists, healthcare professionals, and the public. There are no standard guidelines for clinical diagnosis or management of sound hypersensitivity, and few clinicians have training or experience in working with these patients.⁵ It is not surprising that people with sound hypersensitivity disorders frequently report a lack of empathy, support, and guidance from those who are otherwise best poised to help them.⁶

James A. Henry, PhD, seeks to address this problem in his newly published book, The Hyperacusis and Misophonia Book: When Everyday Sounds Are Too Loud, Distressing, or *Painful.*⁷ His "hope is that this book will bring some clarity about what is known and ultimately help those who are unable to tolerate everyday sounds that saturate our environment." Relying on his 35-year career as an audiology researcher, Dr. Henry guides readers toward a comprehensive understanding of the symptoms, challenges, clinical tools, and possible treatments for each of five sound hypersensitivity disorders. The book is bolstered by a thorough review of scientific literature (with more than 200 references) combined with patient stories and expert opinion.

A Clear Framework for Understanding Sound Hypersensitivity Disorders

A core feature of this book is its clear and succinct working definitions that provide a strong foundation for understanding sound hypersensitivity disorders. Dr. Henry begins "with a working definition of a sound hypersensitivity disorder that would apply to each and all of the individual disorders: A sound hypersensitivity disorder is defined by interference with, or prevention of, participation in normal life activities because everyday sounds cause physical discomfort, negative emotional reactions, excessive fear, or some combination of these symptoms."⁷

He then provides working definitions and high-level overviews of five distinct disorders: loudness hyperacusis, pain hyperacusis, misophonia, noise sensitivity, and phonophobia. The remainder of the book is dedicated to describing each disorder with respect to similarities, differences, and methods of clinical assessment, diagnosis, and treatment. Here, I emphasize what I feel are some of the most unique and overlooked considerations about sound hypersensitivity that this book brings to light.

When Does Sound Hypersensitivity Become a Problem?

A critical component of Dr. Henry's working definition is the consideration that sound hypersensitivity only rises to the level of a "disorder" once it interferes with, or prevents, participation in normal life activities. The sound hypersensitivity literature often overlooks the fact that chronic conditions and physical sensations exist on a spectrum and that "we all live with sounds we prefer not to hear."⁷ As Dr. Henry points out, it is critical to determine not only whether a person's symptoms rise to the level of a disorder, but also where the person falls along the sound-sensitivity spectrum.

To this end, Dr. Henry proposes a scale to infer the degree to which sound hypersensitivity affects a person's life. "We can use the following definitions as a rough guide to diagnose a mild, moderate, severe, or extreme sound hypersensitivity disorder:

- *Mild disorder* = minimally significant interference with normal life activities
- Moderate disorder = substantial interference with normal life activities
- Severe disorder = extensive interference with normal life activities
- *Extreme disorder* = prevents some or all normal life activities"⁷

Pain Hyperacusis and the Limitations of Available Scientific Evidence

Recognizing the degree to which a sound hypersensitivity disorder impacts a person's quality of life is particularly important for people who experience *pain hyperacusis* (also referred to as *noxacusis*). Although the notion that some people experience physical pain when they hear sounds is not new,⁴ this subpopulation has been relatively ignored in the scientific literature for many years and most clinicians do not recognize pain hyperacusis as a distinct disorder that requires special consideration.^{5,6}

According to Dr. Henry, "Pain hyperacusis is indeed a distinct disorder with likely multiple variations." It is critical to understand that, to date, no randomized controlled trials have specifically evaluated the efficacy of any treatments for pain hyperacusis. As Henry points out, recent survey studies,^{6,8} patient testimonials,⁹ and expert clinicians¹⁰ suggest that some patients with pain hyperacusis may experience a worsening of their symptoms after undergoing popular sound therapy interventions that are often used to treat loudness hyperacusis.

Dr. Henry emphasizes the need for a balanced, individualized approach. Most importantly, people with pain hyperacusis should not be pressured to undergo sound therapy intervention, but these approaches should not be entirely ruled out "if and when the person is ready,"⁷ because the ultimate treatment goal is to improve participation in normal life activities. We provide additional details about pain hyperacusis in a companion article (see page 4 of this issue).

When Conventional Wisdom Does More Harm Than Good

People with severe sound hypersensitivity disorders often wear hearing protection devices (e.g., earplugs or earmuffs) even when the noise levels are not considered intense enough to cause ear damage. Healthcare professionals typically discourage excessive "overprotection" from sound, and there is some evidence that prolonged earplug use can lead to heightened sound sensitivity.¹¹

Informed by his own lived experience with loudness hyperacusis, Dr. Henry is one of few experts to formally acknowledge that there are nuances to recommending against the overuse of hearing protection. Whereas "overprotection" from sound is not ideal and can worsen sound hypersensitivity symptoms, some people may need to do "whatever is necessary to survive in a world of painful sound."⁷ People with sound hypersensitivity disorders should never be pressured to stop protecting their ears, and the best approach likely varies from person to person and across symptom subtypes.

Along the same lines, patients with sound hypersensitivity disorders should not be pressured to participate in diagnostic tests (e.g., loudness discomfort level [LDL] testing) that they are not comfortable with and that do not have a clear diagnostic purpose. However, professional organizations¹² and audiologists⁵ commonly cite LDL testing as the primary clinical tool that should be used in the differential diagnosis of hyperacusis.

In brief, LDL evaluations involve presenting sounds that increase in intensity until they reach an uncomfortable level. A person with a sound hypersensitivity disorder may be expected to have a lower LDL than someone who does not have a sound hypersensitivity disorder. However, the scientific literature suggests that LDLs are highly variable across people with hyperacusis and that this type of testing is not sensitive or specific enough to be used as a sole diagnostic tool.¹³ Dr. Henry offers an honest interpretation of existing LDL data and suggests that the risk of causing discomfort often outweighs the limited clinical utility of LDL testing for these patients.

The Verdict: A Resource for Everyone

Dr. Henry has created an accessible and comprehensive resource for sound hypersensitivity disorders that will serve as a bridge between professionals, clients, and the public. The clear working definitions provide a framework to reduce variability in how clinicians assess, diagnosis, and treat these disorders and how medical researchers define and quantify them in their studies.

This book also provides clarity for people who are affected by sound hypersensitivity disorders and validates their lived experiences. Despite the numerous open research and clinical questions in the field, we are reminded not to lose sight of the guiding principle that motivates those of us who are dedicated to understanding and treating these disorders: "The person's quality of life is what ultimately matters."⁷



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"One of the primary reasons that we have many unanswered questions about sound hypersensitivity is that scientists and healthcare professionals do not widely agree on how to define the condition." perception changes across the life span and after injury to the ear. A primary goal of her work is to develop evidence-based diagnostic tools and treatments for sound hypersensitivity disorders, with an emphasis on loudness hyperacusis, pain hyperacusis, and autism spectrum disorder.

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