Issue 2-5 2014

ALLIED Hearing Health MAGAZINE

Musical Ear Syndrome

Cross-Cultural Communication

If I Were a Hearing Person

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ALLIED
Hearing Health
MAGAZINE

Issue 2-5 2014

ISSN 2291-8329

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The *Allied Hearing Health Magazine* is published four times a year by Andrew John Publishing Inc., with offices located at 115 King Street West, Suite 220, Dundas, ON L9H 1V1.

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Allied Hearing Health has always had a pretty clear goal: To make as much information available as possible to people with hearing loss. This can take many forms, personal stories, tips from hearing health care professionals and those who have a hearing loss, and the latest news from some of the outstanding non-profit hearing advocacy groups that span this great country. In short, if there is something or someone out there who might be able to help, we'll try bring it to you.

With that in mind we have an excellent issue for you this time around. Among our regular columnists we have the wonderful Carole Willans who writes about cross cultural communications for people with hearing loss. We also have the always thoughtful Gael Hannan who muses about what life would be like if she were a hearing person. And, the insightful Marilyn Dahl explores the topic of how hearing loss can have an effect on your health and what recent research has discovered.

We also have contributions from two of the most outstanding hearing advocacy groups in Canada in VOICE for Hearing Impaired Children and The Hearing Foundation of Canada, as well as some international content outlining the great work being done by the International Federation of Hard of Hearing People.

And, last but certainly not least we have a fascinating feature article with Rose Simpson talking to Dr. Neil Baumann on a condition called Musical Ear Syndrome.

Scott Bryant
Editor-in-Chief
Andrew John Publishing Inc.

If I Were a Hearing Person...

By Gael Hannan

About the Author
Gael Hannan is a writer, actor, and public speaker who grew up with a progressive hearing loss that is now severe-to-profound. She is a director on the national board of the Canadian Hard of Hearing Association (CHHA) and an advocate whose work includes speechreading instruction, hearing awareness, workshops for youth with hearing loss, and work on hearing access committees.

Gael is a sought-after speaker for her humorous and insightful performances about hearing loss. Unheard Voices and EarRage! are ground-breaking solo shows that illuminate the profound impact of hearing loss on a person's life and relationships, and which Gael has presented to appreciative audiences around Canada, the United States and New Zealand. A DVD/video version of Unheard Voices is now available. She has received several awards for her work, including the Consumer Advocacy Award from the Canadian Association of Speech Language Pathologists and Audiologists.

When trying to remember a time of *not* having hearing loss, I can't. That's beyond the edges of remembering. But I can dream…

If I were a hearing person….
I would wake in the morning, and immediately connect
With the sounds of house-life around me
Husband breathing, cats playing, cell phone vibrating
There would be no noiseless pause as I reach for the jar
Where my hearing aids have slept through the night
And then, once they're in, even the silence has a sound.

If I were a hearing person….
I would not have to stand at the door of a party
Stomach clenched as I prepare for conversations
Saturated with the overwhelming din of the crowd
Not catching the names of strangers or the words of friends
I wouldn't have to copy the smiles of others,
Which are the only things I can understand in this noise.

If I were a hearing person….
I would dine in a gorgeous, dimly lit place
With one romantic candle lighting the face of my handsome husband.
I would understand the server, and maybe order for both of us.
My husband might lean over and whisper in my ear
And I wouldn't need to read his lips.

If I were a hearing person….
The captioning would be off, not covering up
The feet, the faces, the hands and the places
Because these are words I can hear and don't have to see.
At the movies I would follow the action
And not poke my partner with "What did he say?"
Or maybe he'd ask me what a character just said,
And I would never say, *"Sshh, I'll tellya later."*

If I were a hearing person….
Talking on the phone would never have caused
A problem like the one on my very first job,
I answered the phone in the hospital clinic
And said, "Who is this, please – I'm sorry, it's who?
Oh, I'm afraid Dr. Scott is not here, I'm sorry, he's not.
What's that you say? Oh, *YOU'RE* Dr. Scott!?

If I were a hearing person….
I would have heard my partner say, *"Let's get married"*
Instead of seeing his soundless lips shape it.
What man proposes at 6 (in the morning!)
When she's scarcely awake, with no hearing aids in?
He probably just considered it a practice
But I saw and said *yes*, before he could retract it!
        (Don't mess with a speechreader.)

If I were a hearing person….
I wouldn't wear hearing aids that start giving feedback
When you're in a silent elevator ride with strangers
That wouldn't cost some people 1 or 2 or 3 months' salary
and which need batteries that die on the one day your spares are in your other purse.

If I were a hearing person….

I would not have to fight for the right to access – so that I can see a movie, watch TV, understand a lecture, get an education, receive health care, sit on a jury, and do my job… just the same as all the hearing people.

And if I were a hearing person – I might wonder what it would be like to have hearing loss.

Am I asking too much from this dream-hearing-person? In a dream, you're allowed to be anything you want, and this is just an occasional dream – an escape from a bad hearing day. But I'm not a hearing person and really, that's OK.

This article first appeared in the Better Hearing Consumer blog on hearinghealthmatters.org on November 20, 2013. Reprinted with permission.

Guideposts For Research: The Consumer Experience

By Marilyn O. Dahl

About the Author
Marilyn Dahl is the president of the Canadian Hard of Hearing Association BC Chapter

I have always thought of research as proving scientifically what common sense has already told us. So when recent research findings reported that untreated hearing loss contributes to dementia in the elderly, I thought, “Yeah, right, we knew that!” However, we also know the opposite to be true. That is, unrecognized hearing loss is sometimes misdiagnosed as dementia, or at the very least, as stupidity.

For example, recently, an elderly man in the neighborhood triggered a fire in his car because he did not know it had a gas leak. He had not heard the information that the ignition must not be turned on and a service company would be soon coming to tow it away. Neighbours were shouting at him to get away from the vehicle because it might explode, but he just stood there until someone took his arm and pulled him away. Gossip around the neighborhood was what a stupid old man he was. None of them took into consideration his profound hearing loss. Perhaps they were not aware of it.

There is now a growing awareness of how much, and how often the impact of a hearing loss is underestimated. But there is still a long way to go. And, it is not only pertaining to the elderly, but to the rest of the population. In the mid-1990s my doctoral research investigated the prevalence and implications of partial hearing loss in inmates of all of the federal prisons in British Columbia. Over 40% of the adult male population showed some degree of impaired hearing, usually unrecognized. Hearing screening was not a part of the admission physical. Regularly, 83% of the time the ordinary behaviours of those who are hard of hearing were misinterpreted as uncooperative, unruly, and punished.

We have known for years that the incidence of hearing loss in classes for children with special needs is higher than normal. This is also the case for the young in facilities which deal with the young who are somehow in conflict with their society.

The behavioural impact of profound hearing loss is mostly understood, but the behavioural impact of partial hearing loss is poorly understood, even when people know that the individual they are talking to is hard of hearing. The social and economic cost of this kind of ignorance in all of our societies has never been tabulated. Not just the human cost of unintended punishment in prisons and similar facilities, but the fact that group rehabilitation therapies are not effective for people who do not hear well in a group setting. This is a high cost to pay for ignorance.

It is not the hearing loss itself which causes anti-social or aberrant behaviour but likely it is the effects of stressful breakdown in communication which exacerbate the problem. At any age, this leads to isolation, withdrawal, depression, and sometimes acting out.

We in Canada are fortunate that, in some provinces we now have mandatory early childhood hearing screening, with followup. Would that the same could be said for other age groups. A major problem with partial hearing loss is that the individual often does not know they have it, nor do they understand what is happening to their relationships.

Commonly, adults and elders resist getting a hearing aid. Cost is a major issue, but so is attitude towards hearing loss; ignorance; stigma. One does not have to be in prison or be a student in a “special” class, to feel the impact of impaired hearing upon a communication situation. Anyone who is hard of hearing understands the strain of everyday communication. Hard of hearing people who have accepted their condition know that the best adjustment tool they have is to let others know of their limitation and what can be done to facilitate communication.

In other words, the biggest problem experienced by people with partial hearing loss in our society is attitudinal, and that problem is shared equally between the person with the hearing loss and society. Attitudes are gradually changing as more research is done in this field, and the professionals are educated. People with hearing loss need to be educated too.

It is necessary to have research confirm such findings because then it enters the scientific literature, which forms the basis for educating people in a variety of helping professions. It also forms the basis on which governments and other decision makers set policy and develop interventions. So, a tip of the hat to the researchers who ask these questions, pursue these goals. And a note of encouragement to the rest of us, to let researchers know what questions we would like to see investigated.

For example areas in which we continue to need research are:

1. How damaging is hearing loss to general physical health? There is a body of research on the emotional implications, but none which provides a body of evidence on the medical cost of poor physical health due to partial hearing loss. This has tremendous implications when we approach governments for increased subsidies for hearing aid purchase and maintenance.
2. What are the ways in which the media perceives and portrays hard of hearing people and concerns, and how can this be changed? There is poor understanding of the hard of hearing condition by the media in general, and as a result there is no portrayal of hard of hearing issues in any meaningful way. This is connected to lack of public understanding and awareness. Is it also connected to why stigma and denial persist in those not willing to admit their hearing loss?

We have come a long way, there is still a long way to go.

These photos are of the wedding in Tunesia of the authors daughter Caroline Théberge and new son-in-law Sabri Ayari. Photo courtesy Carole Willans and the wonderful bride and groom.

Cross-Cultural Communication

By Carole Willans

About the Author

Carole Willans is a hard of hearing lawyer and long-time advocate for persons who are hard of hearing or deafened. She has a profound bilateral hearing loss, the result of a household accident at the age of four. Carole has been involved in the Canadian Hard of Hearing Association since 1990, during which she served as the executive director, president, and board member.

"Hearing loss" may be a disability; however, the real handicap is at the level of what I call the "communication gap" – the obstacle that arises in the environment as a result of hearing loss. As Helen Keller famously said, "Blindness separates people from things; deafness separates people from people." None of this is news to our readers; however, I would like to address the added challenges posed by the communication gap in cross-cultural interactions.

The International Federation of Hard of Hearing People (IFHOH) and its member organizations naturally engage in cross-cultural communication. These organizations are made up of people from differing cultural backgrounds and yet it has found a variety of ways to communicate effectively, in similar and different ways among themselves. It is fascinating to think that IFHOH and its member organizations do this in spite of having a communication-based disability! Actually, I think that it is their shared experience with hearing disability that helps these organizations communicate across cultures. These groups and their leaders communicate instinctively with much mutual respect, patience and empathy. Much of IFHOH's efforts are also centered on the communication, sharing and leveraging of information, such as its papers on education policy and on cochlear implants.

Like me, you know that it is easier to communicate with persons who "get it" when it comes to hearing loss. As a hard of hearing individual, I meet people every day who, unlike IFHOH and other people who are hard of hearing, do not "get it," and who expect me to somehow "adjust" (i.e., magically hear better) when they communicate with me. Raising public awareness among Canadians is one of the objectives of this magazine and of the Canadian Hard of Hearing Association and its many branches, as well as that of the many other advocates for persons with hearing loss. This has been the work of several decades, and while significant progress has been achieved, this work is still ongoing.

But what happens in the context cross-cultural communication? This, to me, feels like uncharted territory, particularly for persons with hearing loss. For example, and this is a generalization, North Americans come from a monochronic culture, which is manifested in lines at the bank, precise schedules and appointments, and one-on-one conversations (the latter being the preference or need of persons who are hard of hearing, and the "right" of North Americans with hearing loss). In a monochronic culture, you expect (and get) the undivided attention of the person you are talking to, and your business is concluded before someone else's business is started. Otherwise, any interruption is considered rude.

In polychronic cultures (e.g., Latino or North African Arab – again, generalizations) conversations are not linear and are more dynamic. Several conversations are carried out at the same time, rendering it difficult for the North American person who is hard of hearing to follow, and leaving them feeling confused, de-valued, and, depending on the personality, angry or withdrawn. No doubt, it must be difficult for hard of hearing persons in polychronic cultures to function well – I must admit to complete puzzlement about this – however, my focus is on the hard of hearing North American in a polychronic setting. In this situation, it's all about the numbers. If you are outnumbered, there is no way you can require the application of monochronic conversation principles; no matter how hard you try, the circumstances are against you – in fact, if you try too hard, you risk being the one that is being rude in this context.

I have found three ways to deal with this situation. The first is to grin and bear it – and drink my tea thoughtfully, having some fun looking at how communication works in this other culture (however, this recalls my wallflower days as a child and teenager, and I only go there when all else fails because I tend to feel sorry for myself when in that mode). The second is to ask for an individual's help – I call this finding a bit of monochronic in the middle of the polychronic. If it's a hearing person from a monochronic culture, this will be relatively easy, especially if you just ask the person to clue you in as to the general topic of conversation. If it's a hearing person from a polychronic culture, however, be prepared for receiving his divided attention, and don't take it personally. Finally, the third way is active intervention, which is to ask questions, interject without worrying whether it "fits" with what went before – because that is the way the flow of the conversation is going anyway. Even as an extroverted person, I find this last mode of communicating hard to maintain and exhausting, but it is the most rewarding overall. The point here is that you are the one who has to make the adjustment – expecting anything else in a polychronic cultural setting is like canoeing back up a waterfall. When you are back in your habitual monochronic context, remember to go back to requiring your interlocutors to actively participate in the adjustments for meaningful conversations.

It is wonderful to be exposed to other cultures, and to learn about them. Cross-cultural communication for the person who is hard of hearing requires some culture-smarts, by this I mean an awareness that not everyone communicates in the same way we are used to. Before travelling or participating in events in a different cultural setting, read up on this specific topic. Give some conscious thought to adapting your communication strategies. And above all, relax and enjoy!

The Hearing Foundation of Canada visits SickKids.

The Hearing Foundation of Canada Funded Research: Explores the Effects of Cochlear Implants in Children

Recently the staff at The Hearing Foundation of Canada had the opportunity to visit The Hospital for Sick Children, Archie's Cochlear Implant Lab in Toronto, to meet with one of our funded researchers. Dr. Karen Gordon's research focuses on auditory development promoted by long-term cochlear implant use in children.

In this project, Dr. Gordon's team aims to identify differences from normal in brain activity in children who are deaf and use a cochlear implant to hear. With one cochlear implant, these children have the ability to learn how to hear and speak but often have difficulties hearing from a distance and in noisy environments.

A cochlear implant is an electronic medical device that replaces the function of the damaged inner ear (cochlea). Unlike hearing aids, which make sounds louder, cochlear implants do the work of damaged cochlea to provide sound signals to the brain and promote normal auditory development. Yet cochlear implants do not provide complete functionality in comparison to the normally functioning cochlea and have often been provided in only one ear. Dr. Gordon is examining whether these differences from normal hearing might have effects on development on the brain regions which are involved in cognitive and perceptual functions including, hearing, memory and attention.

Dr. Gordon and her team are in a unique position as they are able to investigate this research question by following a group of children who have been using a CI for over 10 years, and measuring their brain activity. Dr. Gordon and her team hope that this work will provide a better understanding of how the developing brain adapts to long term cochlear implant use and will provide the basis for developing new methods to support cochlear implant hearing in children.

The Hearing Foundation of Canada is a leader in the effort to eliminate the detrimental effects of hearing loss on the quality of life of Canadians by providing funding towards medical research in the auditory sciences. This is one of the projects in the recent funding period and was chosen by The Hearing Foundation of Canada's Medical Research Committee. Many worthy projects go unfunded due to lack of resources.

The Foundation's goal is to improve understanding about all aspects of hearing loss - including detection, assessment and treatments as well as opportunities for improved communication. In the long term, we expect to see breakthroughs that prevent hearing loss and restore hearing for individuals of all ages who have hearing loss.

Since 2001, The Hearing Foundation of Canada has invested approximately $1.3 million in more than 50 research projects investigating a wide variety of topics in the auditory sciences, including: tinnitus, improvements in screening hearing loss, hearing restoration, advancements in children's hearing aids and the role of genetics in age related hearing loss, among various other important topics.

THE hearing foundation OF CANADA
La Fondation canadienne de l'ouïe

The Hearing Foundation of Canada is a national non-profit organization. It is committed to eliminating the devastating effects of hearing loss on the lives of Canadians by promoting prevention, early diagnosis, leading edge medical research and successful intervention. For more information, contact us at 416-364-4060 or www.hearingfoundation.ca

Back to School

By Norah-Lynn McIntyre, Executive Director VOICE for Hearing Impaired Children

Back to school is a busy time of year for parents at the best of times, but when your child is a student with a hearing loss there are added factors to consider. Being an informed parent is key to helping to assure that the supports and services are in place for your child. You are your child's best advocate.

VOICE for Hearing Impaired Children has numerous resources to help families to understand their child's needs and also to help understand the role of professionals that can be of assistance to you and to your child throughout their educational career. You can form a unique and rewarding partnership to help to ensure that your student achieves his/her personal best, enjoys learning in a positive and supportive environment and experiences success.

Most children with hearing loss today will be able to integrate into their home school provided they have the help and expertise of trained professionals.

Itinerant teachers of the deaf and hard of hearing are best able to provide support services to meet the needs of deaf and hard of hearing students. Students should receive the amount and type of support deemed necessary, through consultation and collaboration with other team members, to foster successful academic progress and social integration. Factors to be considered will include degree and type of hearing loss and other possible challenges. Each child, school, family and community is unique, and itinerant teachers will best recognize and appreciate the individual strengths and needs of the students with hearing loss they serve. The role of the Itinerant teacher of the deaf is multi-faceted and includes:

- Advocating for and encouraging self-advocacy by students with hearing loss throughout their school years.
- Providing regularly scheduled, direct withdrawal instruction in the development of auditory skills,

speech and language, as required, including the pre-teaching of classroom curriculum.

- In-servicing school teams, including classroom teachers, on the educational impact of hearing loss and making suggestions about classroom acoustics. In-servicing students' peers, as appropriate.
- Liaising effectively with teachers, parents and support staff, such as educational assistants, deaf-blind intervenors, interpreters, and notetakers.
- Developing strategies with classroom teachers to most effectively enable the student to access curriculum. Communicating goals and strategies to parents as educational partners.
- Remaining current in knowledge of technological advancements. Understanding and monitoring the use of all amplification equipment and technical devices and assuring its timely availability through consultation with an educational audiologist.
- Remaining current in grade level curriculum and incorporating such curriculum in the development of foundational speech and language skills.
- Attending team meetings, and helping to collaboratively develop and implement the student's individual education plan. Having direct contact with audiologists, physicians and other allied professionals, as required.
- Providing regular student progress reports, including up-to-date assessment information on hearing loss, cognitive, speech, language, and auditory skills development of the student for the benefit of educators and parents.
- Fostering emotional well-being and encouraging social interaction with hearing peers within the school community. Providing opportunities, where possible, for social interaction among peers with hearing loss.
- Providing information on transitional needs for students with hearing loss.
- Monitoring the academic progress of students using amplification who are not receiving direct withdrawal support through routine contact with classroom teachers.

The support of an educational audiologist can also be critical to enabling your child's full integration into the school environment. Poor acoustics are a barrier in the same way as a flight of stairs is to a person in a wheelchair. An educational audiologist will provide assessment and programming for students in the classroom and, among other things, will also recommend, purchase and maintain amplification technology, including personal FM and sound field systems.

School supports and services are not standardized within Canada nor are they equitable within your community. Informed and involved parents will be able to make a difference in their child's school experience and VOICE is here to help. I invite you to visit:

www.voicefordeafkids.com

voice
for hearing impaired children
50 years

International Federation of Hard of Hearing People

By Carole Willans, Editor, International Federation of Hard of Hearing People Journal

Ruth P. Warick, IFHOH President

The International Federation of Hard of Hearing People (IFHOH) is an international non-governmental organization representing the interests of more than 300 million hard of hearing people worldwide. IFHOH is registered as a charitable organization and is also an International Non-Governmental Organization having special consultative status with the United Nations' Economic and Social Council (ECOSOC). IFHOH is a member of the International Disability Alliance (IDA) and works closely with the UN system using the *Convention on the Rights of Persons with Disabilities* as a tool for change.

The most recent IFHOH Biennial Conference was held April 5 to 7, 2014 in Jerusalem, Israel.

There were many excellent presenters on a wide variety of topics, including the impact of hearing loss within the armed forces, the role of audiologists, and the experiences of children with cochlear implants and hearing aids. The IFHOH president presented IFHOH's paper on Education Policy. At the events in Jerusalem, it was also announced that Dr. Ruth Warick of Vancouver, B.C. was re-elected for a second two-year term as IFHOH president.

The IFHOH Board of Directors has launched an ambitious agenda for the next two years, which Ruth Warick describes as “realistic”. Key commitments include:

- Develop a policy paper on hearing aids
- Establish a global Hard of Hearing Awareness Day for UN adoption
- Embark on a speech-to-text (also known as captioning) project

The next IFHOH Congress will be hosted in cooperation with Hearing Loss Association of America (HLAA) from June 23-26, 2016 in Washington, D.C. People with hearing loss from around the world will attend! All workshops, sessions, and Exhibit Hall will be held at the Washington Hilton, located in the neighborhood of DC known as Dupont Circle. Many delegates will be planning to stay a few extra days! HLAA’s contact about the Congress is Nancy Macklin, director of events and marketing, 301.657.2248, extension 106, nmacklin@hearingloss.org.

IFHOH is busy promoting the rights of persons with hearing loss in a variety of ways. One example is regarding the United Nations’ Millennium Development Goals (MDGs). The initial period for the MDGs is wrapping up in 2015. Goals ranging from halving extreme poverty rates to halting the spread of HIV/AIDS, as well as providing universal primary education, have been worked on for the past decade and longer. Some success has been achieved but more remains to be done.

The Post-2015 Development Agenda is currently being prepared by the UN working with governments, civil society and other partners to build on the momentum generated by the MDGs. Whereas the MDGs did not include persons with disabilities, the International Disability Alliance (IDA), of which IFHOH is a member, is working hard to ensure that, this time, disability is an important part of the Post-2015 framework. These efforts have been on-going for the past year.

On July 8, Ruth Warick, IFHOH president and second vice-president of IDA, participated in a UN panel discussion about *“What can the Post-2015 development agenda achieve for persons with disabilities?”* in New York.

The session was moderated by Corrine Woods, director of the UN Millennium Campaign and among other speakers will be Pekka Haavisto, minister for international development of Finland, Adjima Ghangou, minister of social action and national solidarity, Burkina Faso, and Yoka Brandt, deputy executive director of UNICEF. The session provided an opportunity to highlight the importance of reducing poverty and promoting the equal rights and inclusion of persons with disabilities. Persons with disabilities will not be left behind in the Post-2015 era.

For more information about IFHOH visit

www.ifhoh.org.

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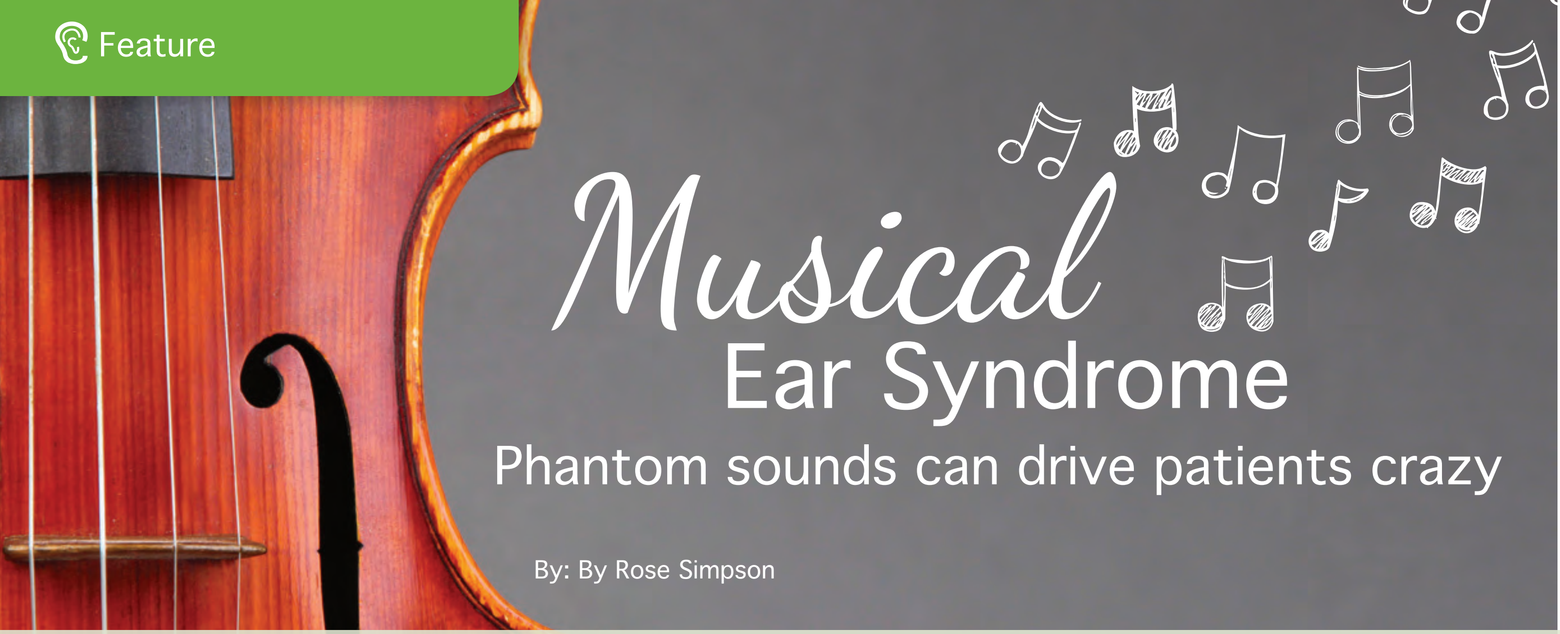
PEOPLE

IFHOH Board: Front row: Duong Phuong Hanh (Vietnam), Ruth Warick (Canada), Avi Blau (Israel); Back row: Louise Carroll (New Zealand), Niklas Wenman (Finland), Marcel Bobeldijk (The Netherlands)



Musical Ear Syndrome

Phantom sounds can drive patients crazy

By: By Rose Simpson

About the Author

Rose Simpson is an Ottawa writer and editor whose work focuses on consumer health and safety and medical professional development. She is the former editor of Audio Infos Canada and Canadian Psychiatry Aujourd'hui, and was a speechwriter for the federal and Ontario ministers of health.

Dr. Neil Bauman is considered a world expert on "phantom music and singing." a condition he says makes some hard of hearing individuals think they are mentally ill.

A man is convinced that his landlady cranks up her stereo after he has gone to sleep. He is so unnerved that he starts banging on her door at 3 a.m. begging her to turn it off. The landlady insists it's all in his head.

A woman hears a radio playing *Silent Night* and other Christmas favourites even though she's taken off her hearing aids. In the summer, she hears *O Canada* over and over again with no radio in sight.

A man is kept awake at night by a bulldozer digging up the neighborhood. He swears the sound is shaking the house, yet when he looks out, the street is deserted and quiet.

Dr. Neil Bauman has been studying this phenomenon for decades and coined the term Musical Ear Syndrome (MES) to describe music and other sounds people hear that simply are not there. The condition is more common than people think, says Bauman, because people are afraid to speak about it, fearing that they are suffering from a mental illness.

"When I speak to groups of hard of hearing people on this subject, I often ask how many of them have heard such phantom sounds. Since they feel safe with me, invariably 10–30% of the people present are brave enough to put up their hands. And that is just those willing to publicly admit they heard such phantom sounds. Others won't even admit it." Those who hear phantom sounds are actually suffering from non-psychiatric auditory hallucinations which are a symptom of something not working quite right in the auditory circuits in the brain.

While someone with a mental illness like schizophrenia hears distinct and clear voices talking to him or having conversations with him, the person experiencing non-psychiatric auditory hallucinations often hears voices that sound like a radio broadcast or a television program. These voices do not talk to the person, nor do they engage in a conversation.

People incorrectly associate all auditory hallucinations with mental illness, says Bauman.

The Fear Factor

"As a result, few people have the courage to admit they are hearing non-psychiatric hallucinations," he says. "Because of this fear factor, many people describe their auditory hallucinations in terms such as 'musical tinnitus' to avoid using the word 'hallucinations'. You see we don't typically think people with tinnitus are hallucinating or being nuts, do we?"

A prolific author and speaker on self-help for hearing loss, Bauman says he coined the phrase to take away some of the stigma associated with the condition.

"Since the vast majority of people who experience auditory hallucinations hear some sort of phantom music or singing, I named this condition Musical Ear Syndrome. Not only does it not have negative connotations, it almost sounds like it might be something good to have – like having an ear for music or having perfect pitch."

Since Bauman coined the term, he has found references to it on more than 6,600 websites and more than 1,500 individuals have contacted him, suggesting that people are now far more will to talk about it.

Definition of Musical Ear Syndrome

Bauman defines the condition as "hearing non-tinnitus phantom sounds (that is, auditory hallucinations) of a non-psychiatric nature, often musical but also including voices and other strange sounds."

It is also different than tinnitus. Tinnitus sounds are single, simple (unmodulated) sounds such as ringing, buzzing, hissing, roaring, clicking, humming, rushing, whooshing, droning and kindred sounds. In contrast, the sounds connected with Musical Ear Syndrome include multiple, complex (unmodulated) sounds such as singing, music and voices. The most common kinds of MES songs are hymns, Christmas carols and patriotic sounds (52% combined).

Bauman says Musical Ear Syndrome is not new, only the name is new. In fact, composer Robert Schulman reported hearing auditory hallucinations near the end of his life, in the form of an angelic choir. He also heard the music of Beethoven and Shubert. His composition Theme (WoO, 1854), he claimed, came from taking dictation from Shubert's ghost.

Characteristics of Musical Ear Syndrome

Bauman has identified a number of characteristics associated with MES.

- **The person is older.** About two-thirds of the people reporting MES are older than 50. About one-third are older than 70. About one-third are under 50 years of age.
- **The person has some degree of hearing loss.** Just over half of people experiencing MES have either mild or moderate hearing loss. Persons with severe hearing loss do not appear to be affected by the condition.
- **Women are more than three times as likely to report it**, though it is not clear whether this is because more women speak up and seek help.
- **The person is experiencing some anxiety, worry, stress, or depression.** One out of five people experiencing MES admits to being depressed before the condition emerged.
- **Most often, people with MES are hard of hearing.**
- **The sound appears to have directionality,** that is, it appears to come from a definite direction.
- **Most people are aware that the sounds are phantom.** Through trial and error, such a putting a pillow over their ear and still hearing the music, many people are able to determine their condition isn't real. One in five, however, are unable to tell that the sound they hear is phantom.

Bauman says Musical Ear Syndrome can often cause irrational behaviour in its subjects, particularly those in their 80s who are unable to separate phantom from reality.

"As a result, they continue to act as though what they are hearing is real," he says. "Unfortunately, because of their apparently irrational behaviour, too often, doctors and caregivers have quickly written them off as 'nuts' and treat them as such.

People believe the sounds are real because they seem absolutely real, they have directionality and they are often accompanied by "tactile sensations" such as the feel of the floor vibrating.

How to Manage the Musical Ear

Here are Bauman's seven steps to managing the condition.

1. See medical attention to rule out brain disorders and other medical conditions.
2. Learn about Musical Ear Syndrome. When you know what you're dealing with, it takes away much of the anxiety.
3. Convince your brain of the falseness of the sounds. When you know your brain is playing tricks, you can put an end to some of the phantom sounds.
4. Reduce your anxiety level. Often doing so can make the condition go away.
5. Rule out drugs. There are more than 360 drugs, prescription and other kinds, which can cause MES. He recommends that patients work with their doctors to determine whether drug side effects are causing the condition.
6. Enrich your environment with real sounds. MES thrives when a patient doesn't get adequate auditory stimulation. Surround yourself with real sounds to listen to all the time. If you are hard of hearing, wear your hearing aids so you can hear something so your brain doesn't produce its own phantom sounds.
7. Become socially active. Increased socialization reduces depression and isolation and gives the mind something else to focus on.

For more information and resources, visit Dr. Neil Bauman's website at http://www.hearinglosshelp.com.