

Changing Perceptions on Hearing Loss on PEI... One Project at a Time

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Being told you have hearing loss can be either a liberating experience (*so THAT's why I'm having trouble following what's going on!*) or something to 'hide' (*OMG, this is career limiting if anyone finds out!*). Many people live in denial of their hearing loss. Others fully acknowledge it privately, but don't make it public knowledge, perceiving a stigma about hearing loss. It doesn't help that hearing accessibility in public places is rarely top of mind when disability access is being discussed or planned.

A few of us on Prince Edward Island are committed to changing perceptions on hearing loss, as volunteers with Hear PEI, a non-profit organization. With limited resources and funding for projects and activities, building awareness and acceptance of hearing loss issues have been key drivers of activities.

I was one of those people who didn't publicly talk about my hearing loss of several decades, as I had heard stories of others having their careers derailed. My hearing loss story began in a taxi, on the way to the airport, where I was on my way to give a presentation in another city. While in the

taxi, I lost the hearing in my right ear. I didn't worry about it as I figured it was temporary. It wasn't, and after I returned from my trip I went to the doctor. That was in October.

By December I had been to see two audiologists. After an MRI I finally was given an answer by an ENT doctor. A medical condition had caused the hearing loss, and it was permanent. This doctor stood out among other health professionals I saw over the years because he took the time to give me material from a non-profit volunteer group, which explained my condition. He suggested I join the group and attend their meetings as it would be helpful. I still have the material and was grateful for it, but never attended a meeting or joined the group. The perception that hearing loss could cause me career problems was never far from my mind.

Once my husband and I were retired, I began to reflect on those early days and realized that in many people's minds, nothing had changed. There was still a stigma. If you have hearing loss yourself, you generally can spot it in another person. I began to wonder why we were putting ourselves through this, and that's what made me decide to help work towards building awareness and acceptance. That first ENT doctor had the right idea decades ago to encourage openness.

Although Hear PEI offers information sessions, occasional seminars with subject matter experts, and ongoing support for those with hearing loss ... the traditional format for peer groups and speechreading classes are promoted, outreach activities play the central role in letting people see that hearing loss does not limit or define a person.

This focus on outreach has helped to bring attention and awareness to a condition that affects the majority of Canadians – whether they have hearing loss themselves or are the family, friends, or coworkers of people with hearing loss – and is the third most chronic condition after arthritis and hypertension. A focus on outreach has also encouraged hearing accessibility champions on the Island to join in the various awareness projects. A few of these projects will be summarized in the rest of this article.

The Pocket Talker Project with the Law Community

One project with PEI lawyers had the goal of improving communications between lawyers and those with hearing loss. This project, funded by the Law Foundation of PEI and supported by the PEI Law Society, had a hefty legal title, but quickly became known as the 'pocket talker project'. It was a deceptively simple project ... participating lawyers were given a few tips on improving communications, a tip sheet was provided for ongoing reference, and they were lent a pocket talker to use with clients who might have mild hearing loss that had not been acknowledged or identified.

One of the challenges identified by lawyers (and other professionals) was hard of hearing clients who do not self-identify and may not have fully comprehended what was discussed. Since a reluctance to self-identify is an ongoing issue with many people with hearing loss, the tip sheets and discussions helped them to identify some of the ways to detect hearing loss informally. Many lawyers said they asked clients to 'help them to trial the pocket talker as part of a project they were involved in', and soon discovered that once people tried a pocket talker they wanted to take it home!

All of the lawyers in active practice ended up buying the pocket talker they were lent, as they found it so useful. The project exceeded expectations and was a win-win for both lawyers and for those with hearing loss. Participating lawyers were very receptive and provided some good tips of their own, which were incorporated into a brochure for clients with hearing loss.

Having a brochure available in the offices of lawyers with pocket talkers was done in the hope to encourage people with hearing loss to self-identify in order to provide the best legal experience possible. Every law office with a pocket talker has these brochures, an excellent suggestion made

by one of the lawyers.

An unexpected benefit of this project was that lawyers began informing seniors' homes and seniors about the pocket talker. This community service has had a ripple effect as once a lawyer was in a facility, the senior homes and seniors wanted to purchase their own pocket talkers. This helps improve their quality of life and reduces social isolation by being better able to communicate.

Lawyers who purchased a pocket talker for their office were invited to have their information posted on my blog, The Aural Report, as a public service to those with hearing loss. (See <https://theauralreport.wordpress.com/pei-lawyers-with-pocket-talkers/>)

Of course, a pocket talker does not address moderate to severe hearing loss, and it is in no way a substitute for a hearing aid or cochlear implant. That being said, the reality, at least on Prince Edward Island, is that many people live in denial and will either not believe they have hearing loss (*everyone else mumbles*), or they feel they can't afford a hearing aid, or they simply refuse to take that step. A pocket talker and tips for better communication builds awareness of hearing loss issues and is a bridge to better hearing accessibility. Once people find that they can hear better with a pocket talker, a hearing aid is not such a scary prospect.

The Let's Loop PEI Hearing Loop Project

While hearing aids and cochlear implants are essential for allowing many people to hear, they don't correct one's hearing, as glasses do. One of the hearing accessibility devices we like for public places is a hearing loop. This device works with an existing sound system, but is not the sound system itself, as many people believe.

What is a hearing loop? is a question often asked, which I find a bit amusing. We don't question how our hearing aids, tablets, cell phones, even cars work, and certainly I couldn't explain the physics or mechanics behind the technology. But a hearing loop always gets questions! Basically, a hearing loop is a copper wire that "loops" around the periphery of a room. It transmits an electromagnetic field within its loop, allowing a hearing aid or cochlear implant's telecoil (also called a T-Coil) to function as an antenna, directly linking the listener to the facility's sound system. The technology is universal, so the same system used on the Island is used world-wide, a very big advantage for anyone who travels.



What is more important to me is the difference in what someone hears within a hearing loop and outside of a hearing loop. If the hearing loop is properly installed, the clarity of sound is unbelievable. For this reason, we always suggest that people with hearing aids ask their audiologist to make sure the telecoil setting is activated and to try one of the places on the Island where a hearing loop has been installed. Kudos to the two churches and the City of Charlottetown's City Hall for being the first to install hearing loops! (See <https://theauralreport.wordpress.com/places-on-pe-i-equipped-with-a-hearing-loop/> for a list of places on PEI with a hearing loop installed.)

Through a grant from the Canadian Hard of Hearing Association Foundation, we were able to initiate a hearing loop project on the Island, which we called Let's Loop PEI, and invited a number of Island audiologists to a session to let them experience a hearing loop and to learn more about it. Our hope is to have audiologists across the county loop a section of their office in order to

introduce their clients to what can be heard.

Unfortunately, not enough Islanders are aware of the sound heard through hearing loops and the number of looped facilities is few. For those that do use the hearing loop, they can't imagine being in a facility without it. If you have no idea what the difference in sound is, here are two short recordings made in a looped church on Prince Edward Island:



LISTEN TO THE DIFFERENCE
LOOPED VS NON-LOOPED

Listen to the clarity of sound through a hearing loop here on PEI, in this excerpt of a presentation by Pieter Valkenburg.

What Was Recorded Through the Microphone By The Front Pew Of The Church:

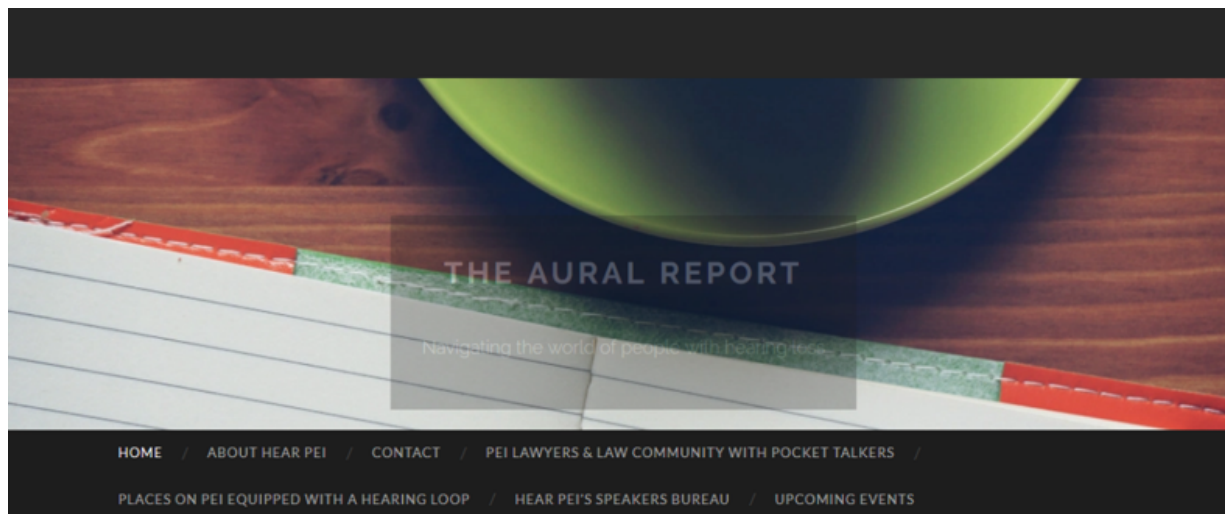
https://soundcloud.com/user-82887253/zoom0013pieternonloopedmp3?utm_source=soundcloud&utm_campaign=share&utm_medium=email

What Was Recorded Through the Hearing Loop:

https://soundcloud.com/user-82887253/zoom0012pieterloopedmp3?utm_source=soundcloud&utm_campaign=share&utm_medium=email

Information Sharing

Over the years, we've prepared pamphlets on various topics related to hearing loss and a booklet on improving communications with and by those with hearing loss. We've even done an emergency management exercise so that emergency management personnel are aware of the challenges faced by those with hearing loss in a stressful emergency situation, and so that those with hearing loss know how they can contact 911. I regularly write articles on topics related to hearing loss for one newspaper. A number of us have been interviewed on the radio on various topics.



People With Cochlear Implants Can Improve Their Ability To Sing In Tune!

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In addition to my blog **The Aural Report** (See <https://theauralreport.wordpress.com/>) we also use email (hearpei@gmail.com) and Twitter (@HearPEI). As volunteers, we can't be everywhere, so these are ways to reach out to a wider audience. Many of the blog topics covered in The Aural Report address questions that people have asked, or introduce readers to products and research related to hearing accessibility.

Another way to reach a diverse audience is with speaking engagements. One of these presentations is '*Living and Thriving with Hearing Loss*,' presented by myself and Annie Lee MacDonald. We not only give some of the basic facts and statistics about hearing loss but share our own hearing loss journeys and how we came to work together in this important volunteer role of promoting hearing accessibility and awareness.

The YouTube Project

Our newest project was to produce fully captioned short YouTube videos on topics of interest and relevance to those with hearing loss. With a small grant from the Seniors Secretariat of PEI we were able to set up our own YouTube Channel and to date have produced six short videos:

- **We Are Your Bridge To Hear** (See <https://youtu.be/zJSQUaeGqsM>)
- **"A Pocket Talker Changed My Life"** (See <https://youtu.be/Jf2xzjwFee4>)
- **Tinnitus Relaxation Therapy** (See <https://youtu.be/I6TBoR69isY>)
- **Holiday Gift Ideas** (See <https://youtu.be/b8OXWQygHJk>)
- **What Is A Car Loop?** (See <https://youtu.be/Ca5cnPPCW64>)
- **"I Love My Looping Chair"** (See https://youtu.be/pioIMAt0_Ww)

The YouTube videos have been an integral part of our outreach activities, and have attracted an audience on three continents....that we are aware of: North America, Europe, and Australia.

The videos discuss various topics: **We Are Your Bridge to Hear** is a brief discussion on hearing loss. In **"A Pocket Talker Changed My Life"**, the late 95-year-old Ruth Brewer talks about the impact a visit to her lawyer had on her life. It was there that she was introduced to a pocket talker and it turned her from being socially isolated to being able to communicate again.

So many people suffer from tinnitus, and when we heard about tinnitus relaxation therapy techniques, we invited a practitioner to demonstrate them. That's the subject of **Tinnitus Relaxation Therapy**.

In **Holiday Gift Ideas**, various products used by people we know are featured in a fun holiday-themed video. This inspired the video "**I Love My Looping Chair**," in which Rheal Leger talked about the chair loop he uses to watch TV. Although we have been encouraging hearing loops on the island, Rheal was the first to purchase a hearing loop product for his home.

In **What Is A Car Loop?** Graham Hocking, a British tourist, demonstrated how he uses a chair loop in his car.

As the grant for making the videos came from the Seniors Secretariat of PEI, the presenters, videographers, and guests were all seniors. We have many more ideas for short videos should we receive another round of funding. We are delighted by the response to the videos and how the conversation turned from a diagnosis that seemed to be a stigma into something that happened to all kinds of people... who are surviving and enjoying themselves?

Success Is Not Always Dependent on Funds

Hear PEI's accessibility and awareness projects have had success for several reasons:

- the interest of the general public is engaged
- the concentration is on positive stories and inclusion, not a perception of victimhood
- professionals such as audiologists and doctors are encouraged to support and participate in awareness building and in sharing new research and ideas
- businesses and professional offices learn how they can provide a better service
- as people with hearing loss ourselves, we share what we have learned and are not there to 'sell a product'
- information and feedback on new products and research is encouraged so we can let others know about them
- people are encouraged to use whatever hearing accessibility tools help them

How Audiologists Can Participate in Accessibility and Awareness Projects

We always appreciate it when audiologists let us know about new products or research they are involved in. Most Island audiologists let their clients know about upcoming events, such as speechreading classes, by putting up a flyer we've prepared.

We encourage audiologists to let clients know about the blog, our email address, and the links to the YouTube videos, and to support the various hearing accessibility projects we are involved in.

It would be great if audiologists could give material from their local non-profit organizations and encourage people to read it and join their group. It was my loss that I didn't listen to my ENT's suggestion to be upfront and join a peer group years ago. If I had to do it over again, I'm pretty sure that I would have made a different decision.