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Understanding health info a challenge for those born deaf



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Angela Mulholland, CTVNews.ca
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If you've just been diagnosed with a new health condition or are trying to self-diagnose a new ache, where do you start? Most of us either call up our family doctors, or "page Dr. Google" by doing a Web search.

More on this topic

- Canadian Hearing Society
- An Examination of Online Health Information Seeking by Deaf People

But when you're deaf, it's often not that easy.

Many Canadians who were born deaf have trouble communicating with medical providers, and while searching the Internet for answers might seem a good workaround, that can often be just as frustrating.

For many Canadians born deaf or hard of hearing, reading English and other spoken languages is not simple. While some have little trouble, many never learn to read English beyond the level of a 10-year-old. And most health information on the Internet is not written for 10-year-olds.

The reason why those who are born deaf often have trouble with complex reading is because reading itself draws on our hearing skills, explains Connie Mayer, an associate professor in the Faculty of Education at York University in Toronto, and a literacy specialist and former deaf educator. If you've never been able to hear, where do you begin with sounding out letters and words?

"You might think of reading as a visual language, because you look at it. But reading is really an auditory process," Mayer explains.

The most commonly used sign language in Canada is American Sign Language, or ASL, and while it can convey all the same meanings as English, it is not a "translation" of English.

"ASL is a gestural language with its own grammar, syntax and lexicon and very distinct from English," she says.

For someone whose first language is sign language, it can be difficult to understand the grammar and syntax of English, and even harder to learn how to read it.

"There are significant numbers of deaf and hard of hearing individuals who learn to develop age-appropriate literacy," Mayer says. "But I would suspect there is a group that would have trouble reading complex text like you might find on a website with health information."

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Language often too dense

Lance Rintamaki, a health communication researcher at the University at Buffalo, has been studying how "culturally deaf" people -- that is, those who are born deaf or who lose their hearing very early in life -- seek out medical information and care.

He's found that many in the deaf community report it can be hard to distinguish what is reliable health information and what isn't. And even when they do find reliable sources, such as government websites, they're often filled with dense and confusing language.

"You often come across many of the same issues with English as a second language in the deaf population that you are likely to come across in the hearing population who are learning English," he says.

As one deaf participant in Rintamaki's study told him: "I really wish there was a web design that would allow you to be able to read the English, but give you the ASL so I can understand the English I'm trying to read."

That's exactly what the Canadian Hearing Society would love to see.

Jo-Anne Bentley, the director of the Communication Devices Program at the society, says deaf Canadians should be entitled to unrestricted access to health information on the Web. And yet, very few health websites offer ASL translation on their pages.

The Hearing Society's own website is an example of what she'd like to see more of on the Web: a site with both text and videos of interpreters "translating" the pages into ASL.

"Our ideal would be to have all information on websites in ASL and LSQ (Quebec Sign Language, the sign language used most often in francophone Quebec)," Bentley says.

Trouble in face-to-face communication

When Web searches fail to yield answers to our medical questions, most of us turn to health care providers. But many within the deaf community find doctor's visits frustrating too.

Not surprisingly, few doctors in Canada know sign language. So deaf Canadians sometimes need to bring along a family member or professional interpreter to act as a liaison. But that's hardly ideal when discussing embarrassing and private medical issues.

Without an interpreter, it can be difficult for many deaf and hard-of-hearing to make themselves understood or to understand what their doctors are saying, Rintamaki reports.

Interestingly, the Internet can actually offer a solution.

Rintamaki found in his conversations with culturally deaf people that many prefer emailing their doctors over the frustration of trying to talk face to face during a rushed appointment.

"The reason why is that some are very conversant in written English, so for them, typing it out is easier than writing it on a piece of paper or trying to communicate verbally, which sometimes leads to confusion and frustration on both sides," he said.

It's not just people who are profoundly deaf who find medical appointments taxing; so do patients who are hard of hearing, says the Canadian Hearing Society's Jo-Anne Bentley.

She notes that in hospital and clinic settings, there can be a lot of background noise and those who are hard of hearing can have difficulty communicating.

"If you can't hear accurately, you can't respond accurately. So the information and diagnosis can be skewed," she says.

Bentley says she knows of situations where hard-of-hearing people have misunderstood directions from their doctors about prescriptions, for example, and have taken the wrong dosages.

Solving this issue first requires training health professionals about how to interact with hard of hearing and deafened patients, by bringing them into quieter areas to talk, for example, speaking slowly and clearly, and writing instructions down.

Her group also works with hospitals about using technology that can ease communication for the deaf. A key tool is something called Video Remote Interpreting, which allows the deaf to have use of an interpreter through a video feed over the Internet.

Bentley says this tool is already proving indispensable for deaf Canadians living in remote areas.

So while the text of the Internet can often present frustrating barriers to the deaf community, its ability to offer video services actually has the potential to solve many of those problems and perhaps transform the way the deaf access health care.



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Cochlear Recipient on

To Earthwatcher - Thank you from the deaf for taking the time to read this article. I lost all my hearing at age 29 from

- the Praires** said
1

a MVA so already could read but in the years since have meet a lot of deaf folk. It is scary how little education there is to teach these to read. ASL is great - but only if you have someone to "talk" to. Would be great for websites to offer ASL and English together so maybe more would learn the complex language of ASL.
- reidjr** said
0

Email doctor - Yes
For people who are hard of hearing email may work but for the masses no it could never work there is just way to many people.
- Email doctor - Yes!** said
6

I am Deaf, while I had stronger education background which resulted in my reading level as adult not an 10 year old level. I still find communication with doctor by face-to-face during the appointment is extremely frustrating. I would agree that there are needs for emailing to be brought into healthcare system. It is time to modernize. Time to bring secured emailing system into it! We all should be able to email doctor easily.
- me** said
3

One thing that is very important when communicating with hard of hearing is to face them when you speak. Don't turn away, or look down or elsewhere. Let them see your mouth. This article didn't address lip reading but I do it a lot.
- Arlene Hache** said
5

Regardless of what people "think", international and Canadian human rights legislation require our federal and provincial governments to make services accessible to people with disAbilities.
- Earthwatcher** said
10

I would never have guessed this problem exists for the deaf. My first reaction to reading the byline was "so whats the problem with reading? don't need to hear to see words, right?" Obviously I was dead wrong and now see the challenge they face.

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