

Banking on your voice: Machine stores speech for patient's future use

August 7 2013, by Elizabeth De Armas

Carole Shearn isn't quite sure when she will lose the ability to speak, but she is sure of one thing: Her voice will still be heard, even when the words can no longer be spoken from her lips.

The 70-year-old West Palm Beach, Fla., resident was diagnosed with ALS, also known as Lou Gehrig's disease, last October. Her form of ALS weakens the [throat muscles](#) first.

The [progressive disease](#) has no cure, but at the University of Miami Miller School of Medicine's Department of Otolaryngology, Shearn is the first patient to take part in voice banking - a program where patients who will eventually lose their voice due to diseases such as Parkinson's, ALS and cancer - can record key words, phrases and personalized messages to communicate when speaking is no longer an option.

Shearn uses Tobii Assistive Technology, a speech-generating device, which stores her recordings into categories. She can then use a mouse, touch the screen or even use her eyes to retrieve the sound files.

In case of an emergency, Shearn has even programmed a message saying "get help immediately" and "call 911." Tobii, which is compatible with Bluetooth technology, will call for her.

"Truthfully, I was so amazed when I found out about the Tobii," she said. "It makes me feel good that I can personalize my messages to whomever. It is my lifeline."

ALS is a neurodegenerative disease that attacks the [motor neurons](#). As the disease progresses, these neurons begin to degenerate and stop [sending messages](#) to muscles. Eventually, individuals diagnosed with the disease lose the ability to move their legs, arms and body.

According to the National Institute of Neurological Disorders and Stroke, 20,000 to 30,000 people are living with ALS in the United States. The average lifespan for a person with ALS is three to five years.

Because ALS patients lose strength and movement in their limbs, Tobii has a built-in [eye tracker](#). Shearn can sit in front of the device - without moving any part of her body but her eyes - and still communicate effectively.

Jocelyn Odlum, a speech pathologist at the University of Miami, met Shearn at an ALS support group in West Palm Beach and then began seeing her at the clinic. After evaluating Shearn, she got her started on voice banking. Shearn has been recording her voice every day for the past two months.

"Carole is an inspiration," Odlum said. "She took this disease and is doing everything she possibly can to be prepared."

Odlum says that once individuals are diagnosed with ALS, they should see a speech pathologist immediately so they can be introduced to these devices and helped. "Unfortunately by the time people come to see me they have no voice," she said.

Shearn has recorded basic phrases such as "Hello. My name is Carole," and "How was work?" But, she also has recorded some of her other favorite phrases: "What's up buttercup?," "What's new, super glue?," and "You snooze. You lose."

When Shearn was initially diagnosed, she had no idea what ALS was. She also didn't know that the disease had no cure. "That was very hard to hear," she said.

"I had tears in my eyes of course and I asked how long I would have to live and my doctor said he didn't know, three to five years, so we left the office on that," she said.

Shearn's daughter, Jennifer Wagner, had been suspicious of early symptoms she had been noticing: slurred speech and choking spells, even when she wasn't eating. She researched her mother's symptoms and learned about ALS.

"It was very daunting and difficult to read," she said. "I had a pretty good idea of what the disease was and what it was going to entail, and I didn't want my mom to go through that."

Although Shearn can still drive and walk without any assistance, Wagner drives her mother from West Palm Beach to the university. She also started an open Facebook page called Carole's Crusade, where people can become more aware about the disease and follow her mother's progression.

"I know that I cannot cure the disease so my main goal is to bring attention to it," she said.

For Shearn, keeping a positive mindset has helped her cope with the disease, but she acknowledges she is not as hopeful and optimistic as she was eight months ago because she notices herself "getting a little worse."

"I was certain I was going to live past 90," she said. "I would still like to." But if she doesn't, Shearn says she feels she has done everything she has wanted to do - traveled to Rome, Alaska, Paris, England, Italy, Spain

and the tip of Africa, been surrounded by good people, and had a successful 36-year teaching career.

"My life has always been about people so I don't crave a lot of outside influence," she said. "Our family is small, but we are tight. That has always been everything to me. I feel my life has been blessed."

©2013 The Miami Herald

Distributed by MCT Information Services

Citation: Banking on your voice: Machine stores speech for patient's future use (2013, August 7) retrieved 20 March 2024 from <https://medicalxpress.com/news/2013-08-banking-voice-machine-speech-patient.html>

<p>This document is subject to copyright. Apart from any fair dealing for the purpose of private study or research, no part may be reproduced without the written permission. The content is provided for information purposes only.</p>
--