

StoryCorps making a difference

Initiative has recorded
more than 50,000
stories since inception

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For many older people, Alzheimer's disease is a cruel twist to their twilight years. Seniors who've spent a lifetime building precious memories with family and friends find those memories being robbed by this slowly advancing disease.

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StoryCorps

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But a unique project designed to document everyday history and the unique stories of Americans is giving many families — and those afflicted with memory loss — the chance to record their oral histories for posterity.

Award-winning documentary producer and MacArthur "Genius" Grant recipient Dave Isay created the StoryCorps initiative, which travels the U.S. inspiring Americans to record their stories in sound. It is touted as the largest multi-year oral history project ever undertaken and since its launch in 2003, StoryCorps has collected more than 50,000 stories.

In 2006, StoryCorps began the Memory Loss Initiative to support and encourage people with memory loss to share their stories. Health First Aging Institute, in conjunction with National Public Radio and the American Folklife Center at the Library of Congress, recently hosted StoryCorps, allowing memory loss patients the opportunity to record their histories.

Charley and Patricia Jorgensen of Cocoa participated in the project at Leeza's Place in Melbourne.

Mrs. Jorgensen, 73, is suffering from the early stages of Alzheimer's disease.

"(Alzheimer's disease) does not run in my family,"



Paul Lepinski/staff photographer

With photos of their children between them, Charley and Patricia Jorgensen pose in their living room.

Mrs. Jorgensen said. "I have no idea why I have it. Just unlucky."

Mrs. Jorgensen's technical diagnosis, labeled "mild cognitive impairment," eventually leads to dementia in 70 percent of afflicted patients.

"I'm hoping I'm one of the 30 percent (who doesn't become affected by dementia)," she said.

The Jorgensens, who have been married for 53 years, had three children — Timothy, Ann and James. James died, but the Jorgensens wanted to preserve Mrs. Jorgensen's past for their remaining children and two grandchildren, Andrew and Emily.

"It's a way of preserving oral history of people's memories so they don't get lost," she said.

The Jorgensens learned about the StoryCorps project after seeing an article in the newspaper about a local memory loss clinic. From there, they found the Health First Aging Institute.

Mrs. Jorgensen had been suffering from mild memory loss for some time before her diagnosis. For example, when showing some curtains to a friend, she forgot the name of the design on the material.

"They were butterflies," she said. "I was having trouble remembering things longer than a few minutes."

She was also concerned when, about two to three years ago, after a minor traffic accident, she was unable to give police important information.

"I couldn't remember my phone number," she said.

"Anytime she gets outside of her normal habits, her memory loss increases precipitously," Mr. Jorgensen added.

"Fortunately, I'm a lot better now that I'm on medication," Mrs. Jorgensen said.

The Jorgensens wanted to preserve their life together, and Mrs. Jorgensen's memory of that life and her family.

StoryCorps provides clients with a list of questions, called the Memory Loss Initiative Question List, which the client's spouse

asks during the recording.

Topics include "family and growing up," "work," "religion and spirituality," "life's joys and concerns" and "an opportunity to share."

Under "family and growing up," one question asks — "You have a photo on your living room table — what is the story behind it?"

"We only ever had one formal photo taken of my family," Mrs. Jorgensen replied. "I found it after my father died. It's very precious to me."

Under the same topic, the questionnaire continues:

"You survived WWII. What do you remember?"

"About all I remember about WWII was my father was drafted and I was told not to cry when we saw him off on the train," Mrs. Jorgensen said.

Other questions and answers detail the hardships of growing up in WWII America.

Finally, as a message to her lifelong mate, the questionnaire offers up the opportunity for patients to express their feelings.

"I'd like to tell you what you mean to me. May I?"

Mrs. Jorgensen says this about her relationship with her husband:

"You mean everything to me, and not just because you are always fixing things. I know that I can count on you ... You comfort me when I am sad. You make me laugh. Sometimes, we hold hands for no reason ... You are my rock. I love you more than anything."

Mrs. Jorgensen said every memory loss patient should take part in the StoryCorps project.

"It's important," she said, looking at her husband.

As part of the project, the Jorgensens gave permission for excerpts of the recording to be broadcast on NPR. StoryCorps excerpts air about once a week. The stories were also collected and archived at the American Folklife Center of the Library of Congress.

For more information on StoryCorps, visit their Web site at www.storycorps.org.