

Mixed Media

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Gathering Memories While One May: A Narrative on Creating Personal and Public Oral History Collections with Alzheimer's and Other Dementia Victims

By Jim Havron, CA, Cultural Heritage Cyber Preservation

Within my business I was able to develop a project to serve Alzheimer's and other dementia sufferers by recording their thoughts and memories and providing them to their families. I believe it to be unique in its focus and execution. Interviews are conducted using standard practices for audio recording, with occasional additions of video. The interviews often include a small group of people, so the recording setup takes that into account as warranted. This is a narrative account of what and how it is done, with the understanding that each situation is different, and each experience must be adapted accordingly.

I generally work on the interviews, along with a network of professionals and trained volunteers. I also provide the equipment, unless an unusual situation calls for something beyond available resources. Redundant storage of the resulting files, including significant security, is also provided. The project is designed to create a private collection for participants, while offering the opportunity to make them available for research at other repositories.

Our aim is to conduct audio interviews only. There are numerous reasons not to record video, chief among them being larger preservation issues with digital video, interviewees being "camera shy," and handling multiple people in an interview. If video is used, a separate audio file is created as well.

We record interviews in digital format, double-mono, 24-bit, 44.1 kHz, PCM/WAV. The recorder of choice is a Marantz PMD661 with an SLR microphone. A dynamic microphone specifically designed for the "speaking voice," the Electro-Voice 635A/B is omnidirectional and was used along with the Marantz PMD561, which is about the size of a deck of poker cards.

The interviews themselves are somewhat standard oral histories, but we invite family members to participate so they can ask their own questions. In such cases, we use a microphone stand designed to be used with a base drum. The stand is low to the ground, while its longer boom allows it to be positioned away from the group just a bit while placing the microphone itself in a better position to capture the sound.

Our network has adjusted to provide for unexpected aspects of specific interviews. In one instance, we recruited a guitar player to play some music requested by the interviewee because he wished to discuss why the songs meant so much to him. One woman wanted a recent photograph taken before she was too "wasted away" [her words], something we could provide because we have a professional photographer in the network. The photograph was there during the interview and helped to stir memories for her story.

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The preferred recorder is the Marantz PMD661.



Inputs on the Marantz PMD661



The smaller Marantz PMD561

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We added a new feature to the project after interviewing a man in the early stages of Alzheimer's. As his disease progressed significantly, he reached a state where he was always confused, unable to communicate, and frequently angry. The one part of his former life to which he was still able to connect was the ability to play the guitar to some degree, and it was his wife's wish that his playing be recorded, but his unpredictability made this difficult. Purchasing Zoom H2 recorders for this project was one solution. These are small recorders with acceptable internal microphones and less complex settings than the Marantz recorders. One was configured with all the appropriate settings, so all that needed to be done to record was to press the record button, then pause or stop. The man's wife was shown how to use it, and it was set on a counter near where her husband generally spent his time. Any time he started to play, she could record. In this case, the record-

ings were in .mp3 file format, smaller than the usual WAV files, because we didn't know how much space would be needed. They eventually recorded around 50 files, many under 7–10 seconds, many longer. There were enough longer files to make a multitrack CD/album of about 20–25 minutes, which we produced as "The Very Best of [identity guarded at present]." The family was thrilled, and we kept this service in an arsenal of tools for later use. At the time of this writing, all three of the Zooms are on loan to people in different parts of the country.

Medical staff sometimes use the recordings in treating patients, either to record background information to better inform a doctor about the patient, or connected to the journaling therapy that has become a standard part of treatment in many such cases. This can be considered more anecdotal than proven medically, yet it does open a door on other possible benefits of oral history.



The Zoom H2 and other equipment

In this kind of work, ownership and use of the product poses challenges. No specific requirements are made prior to the interview, which we bring to the participants' attention with the hope that they would be willing to make a gift of the final product to our repository to provide access to researchers and others who may be interested in the content. We have a Creative Commons (CC) license where copyright restrictions on use are surrendered to the immediate family at the time of recording. This assures the donor that the gift of the interview will be used in the manner agreed upon, and a third party cannot assert control based upon some perceived personal right if none of the original participants are accessible. Conditions of use and ownership are negotiated in each case. The deed always states that the archivist, or appointed successors, will do all that can be done to preserve the digital files for as long as possible based upon his or her resources and professional judgment as an archivist and information systems professional. If agreed upon, interviews are placed in an archival repository for research and preservation. Various options can be arranged to transfer rights or establish a license, from a CC license that essentially gives both parties full or limited use, to donation of copyright, to donation with restriction on identity for a set number of years, to no donation at all.

Most participants either surrender copyright entirely, use a CC license to be executed upon the death of one of the family members, or use a CC license to be executed 20 years from the date of the recording. Different trust levels develop during the process, and some participants start the process by transferring copyright while others who had originally restricted use execute the transfer agreement earlier than expected. One family participant decided the interview was of too personal a nature and decided to retain all rights, but to date, all others who have not yet executed an option have signed one that will eventually go into effect. Custodianship of the files is still retained by the archivist, who will readily discuss those details with any who ask.

The last technical feature of the project is an access one. We use Audacity audio editing software due to its ease of usage, despite the existence of other more sophisticated apps. Using this makes it possible to create an "archival" (WAV or AVI on gold disk; allegedly higher quality and longer lasting) and disk storage in both .mp3 and audio CD formats. When copies are requested, the team prepares clips deemed particularly interesting. These are available

should someone wish them for funeral or memorial purposes.

The goal of this project is to preserve history for personal purposes, hoping that it will be available for all. It involves adapting to unusual circumstances that may have no connection with traditional best practices. Control of the end product is in the hands of the nonarchivist party; yet, we have the beginning of an unusual collection. The collection is growing slowly. Although we offer the recording service often, the time of life when patients are most able to do interviews is also the time when family has more on their plate and can often be in denial. Frequently, they return when it is too late and say they had accepted my offer. So, using very similar guidelines, I am now also collecting interviews from surviving family members.

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