



# Alive Inside Outreach: Advocacy through Community Service

By Chip Staley

*There is a growing population of elders living with dementia and memory issues. This article will explain how Alive Inside Outreach can benefit these individuals through service with music groups such as the Tri-M Music Honor Society®, which focuses on creating future leaders in music education and advocacy. For more information on Tri-M, please visit [www.musichonors.com](http://www.musichonors.com); for information on Alive Inside Outreach, please visit [www.aliveinside.org](http://www.aliveinside.org).*

## Living with Dementia

***Musical memory is stored in the last part of the brain to die.***

Dementia is a general term to describe brain disease that is degenerative, irreversible and incurable; Alzheimer's is the most common form of dementia. As the disease progresses, brain cells die from the outside of the cortex to the interior of the brain. Musical memory is entwined with language, visual and experiential memories and stored in the auditory cortex located in the very center of the brain. The auditory cortex is the last area of the brain to be impacted by Alzheimer's. Consequently, elders with Alzheimer's have access to musical memory as long as they are alive.

I first became aware of the impact of music on the brain through my wife, Lynne, and her volunteer work for Metropolitan Family Services over a decade ago. She served as a companion for elders with dementia to provide respite for their caregivers. To pass the time, she would listen to music with them, and in doing this she tripped over the astounding effect music can have on elders living with dementia. The heartwarming anecdotes of her elder's responses to music from their youth, one scat singing along with Glenn Miller tunes and another singing lyrics to the entire Hank Williams anthology, moved and inspired our family. So when the agency sponsored a screening of the documentary *Alive Inside*, Lynne encouraged me to attend with her.

The film "Alive Inside" provides an in-depth look at the benefits of activating musical memory. Director Michael Rossato-Bennett captured on video the impact music playlists had on elders living with dementia. Rossato-Bennett's camera follows social worker Dan Cohen as he helps elders listen to music from their youth. Finding just the right music will temporarily bring back memories entwined with the music to the elder. Those who were once mute and non-responsive become animated and talkative. The philosopher Immanuel Kant defined music as the "quickening art," causing people to "come alive" with the memories of their past. A YouTube clip from *Alive Inside* titled "Henry Responds to Music" ([goo.gl/gxrwXe](http://goo.gl/gxrwXe)) has over two million views and offers the most dramatic example of this phenomenon.

Watching *Alive Inside* was an emotional experience that moved me to tears and galvanized me. I immediately volunteered to be a part of the Music & Memory™ Certification Program. That experience eventually led me to the Alive Inside Foundation and influenced me to begin an Alive Inside Outreach program serving Naperville and Aurora.

## The Benefits of Alive Inside Outreach

In the United States, 5.5 million elders suffer from Alzheimer's. The number of elders afflicted is expected to grow to over 18 million by 2050. Stunned by the magnitude of this statistic,

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Michael Rossato-Bennett founded the not-for-profit Alive Inside Foundation to help increase awareness of this devastating disease through the Alive Inside program. To that end, the foundation offers a template for educators to implement a program designed to connect teens to elders living with dementia.

As music educators, we are in a unique position to help increase awareness of this disease with resources such as Alive Inside. The role music plays in our brain provides a powerful argument that music is an essential part of our lives. The Tri-M chapters at Neuqua Valley and Waubonsie Valley High Schools sponsored by Brad Pfeil and Daryl Silberman recognized the potential of Alive Inside Outreach to energize their members. It provides an opportunity to engage in meaningful community service that enriches the lives of high school students and the lives of the elders they serve.

### Implementing Alive Inside Outreach

Alive Inside has developed a comprehensive curriculum to help prepare students to interact with elders. Students learn about dementia and how to elicit enough information about their elder's musical tastes and experiences to compile a personalized playlist. ([goo.gl/2nbjf4](http://goo.gl/2nbjf4))

Using the curriculum, TriM sponsors will find it rather easy to create a training program that meets the needs of their students and the elders they serve. The specially created app ([goo.gl/FBrz1b](http://goo.gl/FBrz1b)) helps students generate song titles and artists most likely to reinvigorate their elder. The playlist is legally downloaded and saved onto a Micro SD card that is inserted into a specially designed mp3 player built into elder-friendly headphones ([goo.gl/DSfrjz](http://goo.gl/DSfrjz)). Students deliver the headphones loaded with music and sit with their elders for a shared experience listening to the playlist and rediscovering lost memories.

### Funding

Once an Alive Inside team is established, it is easy to inspire members of the music department to raise funds necessary for headphones, mp3 players, iPods and iTunes gift cards. Waubonsie and Neuqua were able to collect equipment and more than

\$1000 in donations. Speaking at community service organizations will likely generate contributions. For example, I was invited to speak at the Rotary Club of Naperville and they immediately wrote a check for \$1000 to pay for all of the equipment needed to run the program for the 2017-18 school year. Advocacy groups will also embrace this project. The not-for-profit ART-Speaks ([artspeaks.net](http://artspeaks.net)) accepts donations and disburses funds for our Alive Inside Outreach program. There will be no shortage of funds to implement the program once a core group of people in the community is sold on the idea.

### Community Partnerships

Every community has a need for this program; finding a place that serves elders living with dementia, with managers and caretakers willing to host an Alive Inside team, can be challenging. We partnered with the Naperville Senior Fitness and Activity Center for our first Alive Inside experience. The owners, Pam and Mike Cooper, offer day services for elders and were delighted to open their doors to our students. They helped us match

the elders with the pairs of students and determined the optimum time of day (after lunch) and length of visit (45-60 minutes) to most successfully work with the elders. Not surprisingly, the elders and students were always reluctant to end the visit.

### Team Composition

Alive Inside guidelines recommend that the optimum size of a team be comprised of 10-20 students. The students work in pairs to serve between 5 and 10 elders. Pairing up makes the students more comfortable when they meet the elder for the first time. It also allows one student to talk to the elder while the other can participate in the conversation or handle logistics.

"It's funny, they call this program Alive Inside because the elder 'comes alive.' But I think that we also 'come alive' when we witness music bringing elders up, out and back to who they once were."

- Elena S., Neuqua Valley TriM Member

### Training

The curriculum provided by Alive Inside Outreach can be distilled into 160 minutes of formal classroom instruction and 120 minutes of video resources. I recommend four weekly afterschool classes for training of the high school students. This allows students an opportunity to view video resources between each session. Students are required to watch the documentary *Alive Inside* before

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the first class. It is important to see the film because it will provide a common understanding of the importance of the service the students are being trained to provide and the positive impact they will have on the elder's lives.

The first classroom session is an overview of the program including an explanation of the mission of Alive Inside Outreach and the implementation plan. Students discuss their reactions to the *Alive Inside* documentary and discuss the different types of dementia like Alzheimer's, Vascular dementia, Lewy body dementia and Parkinson's. Students examine illustrations of healthy brains and demented brains to help students understand how the disease impairs much more than just memory. While it is not important to know every detail of each variation of brain disease, it is important to help students understand that the disease and its symptoms are different for every individual. This prepares them to expect unusual behavior or communication problems when they meet their elder for the first time.

The second classroom session focuses on communication protocol between team members and their elders. Students discuss common errors neurotypical people make when interacting with individuals with dementia. This session prepares students to understand and empathize with elders, and to see them as people who are not defined by their illness. Great resources for this session can be found at [www.teepasnow.com](http://www.teepasnow.com). Teepa Snow's videos describe in plain language, and in great detail, what it is like to suffer from dementia. Teepa challenges viewers to value and honor elders by focusing more on what they are able to do than on what they are no longer able to do.

The third classroom session continues the conversation about the guiding principles of empathy; mindful communication, non-verbal strategies, verbal strategies, behaviors to mindfully avoid and demystifying behaviors. In this session, students role-play and act out conversations, social interactions and think about how to respond in different situations.

The final classroom session focuses on preparing for visiting elders and creating individualized playlists. Students discuss strategies for setting the tone for a genial conversation and gathering pertinent information using Alive Inside interview questions and the Alive Inside App ([www.aliveinside.org/app](http://www.aliveinside.org/app)) to create a playlist.

### **Elder Visits**

Following the training, there are four visits to the elders. The first visit is designed to introduce the elders to their team and to talk about music. The second visit is to deliver the playlist and be present for the conversation that naturally results. This is a magical time for all participants.

The teams commit to two follow up visits that they schedule on their own to cement a relationship with the elders and observe the long-term impact of the playlist. Team members consider this a life-changing experience and express their enthusiasm to become leaders for the next group of Alive Insiders.

## **Impact on Student Participants**

Nilesh M., a member of Neuqua Valley's Tri-M Honors Society, explains, "When I was interviewing Tom, his answers came in bits and pieces. But, as soon as he heard 'Joey, Joey, Joey', he spoke in complete sentences and his stories started to flow from him. Seeing him sing and his eyes water up after listening to that song truly made my week. He was ecstatic. He talked to me about the importance of music and family. I haven't cried in five years, but I came really close when he told me that my visit added a bit of both music and family to his life."

McKenna J. is another member of Neuqua Valley's Tri-M Society, and this outreach has a very personal impact on her life, and the lives of family members. "I've seen videos of people who have had strokes and lost all verbal-communication abilities speak whole sentences by singing 'Itsy Bitsy Spider.' I have seen videos of people barely able to walk who have begun speed walking to the beat of their favorite song. I have seen my Papa, who is in the fourth stage of Dementia, wake up from a nap, start smiling with his single remaining tooth, tap his non-ambulatory feet, and laugh, just from hearing me play the flute. I will never be able to fully explain how music can move us to do things we thought we were incapable of doing. That is why I would like more people to know about this program. I want others to experience the magic that is music, and the places it can take us."

## **The Empathy Revolution**

There is a tremendous need for empathy for elders suffering from dementia so their needs can be compassionately addressed as the disease progresses. There is no better place to build empathy than with young musicians. Alive Inside Outreach provides the model for what the foundation describes as an Empathy Revolution.



*Chip Staley is a retired music educator, having spent most of his career in the Naperville 204 School District. Staley is the founder of ARTSpeaks, a grassroots organization dedicated to cementing the role of music as an essential component of a comprehensive education. Chip directs the Merit School of Music's Wind Symphony in Chicago and serves as a Conn-Selmer Clinician.*

*Tri-M sponsors thinking about beginning Alive Inside Outreach for their school are encouraged to contact Chip Staley at [musicandmemorydupage@gmail.com](mailto:musicandmemorydupage@gmail.com). He is happy to answer any questions and help you get started!*

*To see Arts Inside Outreach in action, please find these clips on YouTube:*



*Highlights of Alive Inside 2017: [goo-gl/HJTtwj](https://www.youtube.com/watch?v=goo-gl/HJTtwj)  
Alive Inside 2017 Full Presentation: [goo-gl/5VdvbT](https://www.youtube.com/watch?v=goo-gl/5VdvbT)*