

THE VOICE OF PATIENTS AND FAMILIES

Finding Joy and Purpose Through Singing: Giving Voice to People Living With Dementia

Barbara Greene, MPH
Marge Ostroushko, BA
Jodi Melius, RN

For every individual living with dementia, the experience is unique. When you meet one person living with dementia, you have simply met one person. Dementia will change many things about life—but not all at once and often over many years. For many people, social isolation and loneliness may emerge as mental health challenges occur. This is when creating supportive interconnections are particularly critical to build meaning and purpose. *Giving Voice Chorus* was created in 2014 to address social isolation for people living with dementia. Our choruses, and other like-minded ones throughout the United States and the world, support new networks for people living with dementia, as well as their family members and friends. This is a behind-the-scenes story of how *Giving Voice Chorus* and a strong collection of similar choruses help meet cultural, social, geographic, and community needs for people who are determined to continue vibrant, creative lives with memory loss. We explore how these choruses developed and the creative lifeline they provide for individuals and families. For health-care professionals and others seeking resources and referrals, *Giving Voice Chorus* is a beacon of light—establishing new supportive networks with hope and affirmation.

Keywords: *Giving Voice Chorus*; Alzheimer's disease; dementia; music; care partners

"Music is part of being human."
(Oliver Sacks, 2008)

It is quiet in the street outside the MacPhail Center for Music in downtown Minneapolis, Minnesota. The Center is airy, spacious, and flooded with light. At their weekly rehearsal, voices of singers—sopranos, altos, baritones—are heard practicing *a cappella* scales. To a visitor, the rehearsal may appear like any other. Under a director's guidance, the chorus begins with warm-ups, exercising their vocal cords and preparing for the session ahead. The singers are casually dressed and have expressions of anticipation on their faces.

But this is not just any chorus. This is the Twin Cities' *Giving Voice Chorus*, composed of individuals living with Alzheimer's disease and other dementias, and their care partners, who are family members and/or friends. Chorus volunteers sing alongside the singers, offering support as needed. In fact, the group has become a community of singers.

Since 2014, more than 50 choruses for people living with dementia have been formed throughout the world. Their repertoire includes jazz, gospel, musical theater, folk, and popular selections, often reflecting the cultural backgrounds and interests of the singers. This is the story of *Giving Voice Chorus* and other like-minded choruses—a story about the creative power of music that builds community, breaks down stigma, and fosters relationships. It is also a testimonial to living with purpose—a basic human need for everyone regardless of their health or age.

This article focuses on how singing in a professionally directed community chorus, designed for persons living with dementia, can reduce social isolation and stigma. It describes cultural aspects of the choruses and how history, language, and community impact the singers. Readers will explore how to create supportive environments for the singers; the benefits

of empowering singers with an asset-based approach; and how health-care professionals can be proactive in supporting individuals living with early- to mid-stage Alzheimer's disease and other dementias.

LIVING WITH DEMENTIA

For every individual living with dementia, the experience is unique. When you meet one person living with dementia, you have simply met one person. The symptoms, rate of progression, and challenges vary widely. Diseases that cause dementia include Alzheimer's disease, Lewy body dementia, frontotemporal degeneration (also called frontotemporal dementia), vascular dementia, and mixed dementia. Each has distinct and important differences (National Institute on Aging, 2021).

Dementia will change many things about life, but not all at once and often gradually over many years. Angela Lunde, Program Manager in the Mayo Clinic Alzheimer's Disease Research Center, has been mentored by persons living with dementia for more than two decades. She explains, "People living with dementia tell me that a good life is less about remembering an event that happened a few days ago or remembering someone's name. Rather, a satisfying life is about having strong supportive connections and feeling like we contribute to something or someone in a meaningful way" (A. Lunde, personal communication, May 16, 2022).

In addition to the physical symptoms and behavioral changes, other challenges include societal stigma and community isolation that deal equally harsh blows. Our society's reaction to dementia often includes fear and stigma that crosses racial, cultural, generational, class, economic, and gender identification borders (Aboseif & Woo, 2020). Dementia is frequently a diagnosis that many families and communities try their best to hide. With this hiding, a social desert looms. There is a loss of identity. Friendships fade away. Professional and community connections and purposeful activities diminish. A new kind of dependence emerges. A very different life begins to take shape that is frequently unsettling and without satisfying answers about what comes next.

When music enters the picture and singing in community begins, hope and a renewed sense of purpose emerge. With the guidance of a trained choral director who focuses on the strengths and assets of persons living with dementia, each singer discovers appreciation and meaning. In spaces across the United States and

our world, persons living with dementia are experiencing a rebirth with the joy of singing together.

CREATING SPACES OF WELCOME

In the Minneapolis and Saint Paul metropolitan area, *Giving Voice Chorus* rehearsals are held in spaces that are welcoming, filled with natural light, and accessible for older adults. Each chair has a singer's name written on a sticky note so that everyone knows where to go with greater confidence.

Singers range in age from mid-50s to 90s. Each singer comes to rehearsals with a partner—a spouse, friend, neighbor, and/or relative. In the first few rehearsals, partners sit and sing next to each other, but over time, they often separate into preferred vocal sections: soprano, alto, and baritone. With this change, chorus volunteers sit next to the singers with dementia, providing support in many ways, such as turning pages of the music score and using a strong singing voice to help lead the way. Volunteers often become important new friends whom singers look forward to seeing each week.

Most songs are in three-part harmony. Sometimes arrangements are created specifically for the chorus members. Singers learn through repetition during rehearsals, and practice with CDs or videos at home.

Music directors of *Giving Voice Choruses* have a wide range of experience working with older adults. They are deeply engaged individuals who inspire laughter and help create joy during each session. They seek ideas from their singers for musical preferences when choosing songs. The focus is on teaching choral techniques as well as evoking a sense of joy, belonging, and accomplishment. Many *Giving Voice Choruses* follow the mantra, "There is no wrong in the room!" This phrase reinforces a choral culture that accepts mistakes as part of learning. Chorus members frequently comment on the openness, creativity, and encouragement they experience.

Because living with dementia is often isolating, having time for socializing at each rehearsal is important to everyone. Over refreshments, singers, care partners, and volunteers talk freely about their week and their experiences. As one singer explained, "Outside of the chorus, everyone tries to do things for me. This is one place where I am seen as a whole person and capable of doing things myself."

Singing Across Cultures: A Latinx Perspective

Centro Tyrone Guzman is a social service organization serving a diverse Latinx population in the Minneapolis/Saint Paul area. Elders make up an important part of their clientele. Elders from Mexico, Puerto Rico,

Colombia, Honduras, Nicaragua, Peru, and other Spanish-speaking countries come together to share their traditions and histories at Centro.

Twenty elders, some with memory loss, sing together in Centro's ongoing *Wise Elders* program chorus. The program's name signifies the respect and importance of elders throughout the Latinx community. In addition to singing, chorus participants find purpose, joy, and connection in other ways. They dance. They tell stories. They build community. Every week for two hours, the chorus elders gather in person or virtually. During the COVID-19 surge, this chorus learned to navigate Zoom technology for meeting and reconnecting. Vladimir Garrido-Biagetti, a talented artist, dancer, and singer of traditional folklore from South America, is the artistic director of the chorus. He plays a variety of instruments and encourages all participants to move physically and to dance. He is also their Zoom technology coach during the session. He is loved by the group.

Yolima Chambers, director of Centro's *Adult and Aging* program, points out that dementia has a powerful cultural component for many Latinx people.

Dementia and Alzheimer's are words that are not liked within our community. They have a very uncomfortable meaning. For many, these words symbolize being "crazy." Many Latinx have never had access to essential health education and support for memory loss. Many have no health insurance, so an actual diagnosis may never take place. When we talk about memory loss at Centro, we do so with hope and compassion. We provide culturally significant, dementia-friendly education and resources. We focus on what is possible so families can avoid any shame or judgment that so often occurs. We know that music brings out the best in everyone; it is a common denominator across cultures. Through the sharing of song and the joy it creates, our chorus members and families know that this chorus and our staff are there for them. (Y. Chambers, personal communication, January 19, 2022)



The *Wise Elders* Latinx program chorus embraces music across cultures.

Amazing Grace Chorus: An African American Model

Within a choral model, there is space for flexibility and adaptation, especially to honor heritage and culture. In the *Amazing Grace Chorus* in Saint Paul, Program Director Shana Moses recognizes that for centuries, song and music have been essential for people of African descent. Music served as a powerful form of communication for Black people from Africa to the Americas. The 30+ members of the *Amazing Grace Chorus* include elders with and without memory loss; Moses explains that this historical perspective is integral to all.

Music brought Black people together from distant shores and helped unite and sustain them during horrific times. It continues to teach new generations an important shared language and oral history. It also continues as a uniting force in African American churches and communities. Some of our singers in the *Amazing Grace Chorus* are highly accomplished musicians within their own church communities. They were often leaders of the call and response style of gospel music. Though gospel music has evolved, in our chorus we intentionally draw from traditional gospel songs of their past to unearth cultural knowledge, memories, language, and stories. This has helped our members rediscover their strong voices and their important perspectives. (S. Moses, personal communication, February 8, 2022)

Collectively stretching their notions about memory loss and aging, the chorus is now forming new partnerships with African American faith organizations, schools/universities, and community organizations. According to Moses, the group has exceeded all expectations.

We began as a handful of singers and elders; now we are a family. Our time together marks the telling of new and old family histories, stories, and check-ins on health and wellbeing. We share our talents deeply and freely. While memory loss may be an issue in our lives, it does not define us. Our *Amazing Grace Chorus* is truly a chorus of grace. It brings together the best in all of us through a shared music identity. At a time in our lives when isolation often takes hold, this chorus is truly a healing balm. (S. Moses, personal communication, February 8, 2022)

Within a choral model, there is space for flexibility and adaptation, especially to honor heritage and culture.



Members of *Amazing Grace Chorus* at the Walker | West Music Academy in Saint Paul.

A LIFE OF PURPOSE

What does it mean to live with purpose? While ways of living with purpose may change over a lifetime as we age, the need for purposeful living never diminishes. For many years, health-care researchers, sociologists, and psychologists have studied the impact of living with purpose and its connection to well-being. This is particularly true among aging adults and those living with Alzheimer’s disease and other dementias. Boyle et al. (2012) stated that “...participants who reported higher levels of purpose in life exhibited better cognitive function despite the burden of the disease” (p. 499); thus it is not only possible to have purpose while living with dementia—it may be *essential* for ongoing health and well-being.

The inclusive choral model championed and shared by *Giving Voice* and other like-minded choruses is one way for persons with dementia and their loved ones to find purpose. In each chorus, the director and singers depend on and support each other. Each chorus works hard to create engaging music, sharing in the fun through voice, song, and socializing. At the end of each semester, many of the choruses perform a public in-person or virtual concert, and also receive requests to perform at special events.

Prior to the COVID-19 pandemic, more than 170 singers in the combined Minneapolis/Saint Paul *Giving Voice Choruses* performed to a sold-out audience at the stately Ordway Center for the Performing Arts in Saint Paul. In early March 2020, the *Resounding Voices Chorus* in Rochester, Minnesota collaborated with a local high school choir in an intergenerational performance that gave student singers the opportunity to learn about dementia and societal stigma. One student who sang in the *Resounding Voices* concert offered this enthusiastic comment: “All the music, and

“While memory loss may be an issue in our lives, it does not define us; we are truly a chorus of grace.”

bouncing from different genres and different harmonies, it was pretty incredible. The dementia isn’t what defines them.”

A consistent theme that audiences and chorus observers share is, “I can’t tell who has dementia and who doesn’t!” We believe that this awakening takes place because all singers are sharing a powerful experience of engagement in creative song. These public performances give families and communities a chance to support dementia-friendly living and purposeful engagement.

A VIEW OF OUR FUTURE

The *Giving Voice Chorus* model and experiences of like-minded choirs are creating a new global movement of inclusive engagement and creativity for persons and family members living with memory loss. Through shared community and empowerment, singers, their care partners, and community volunteers have moved beyond a deficit-centered and stereotyped mindset. We can become much more proactive by supporting our communities and families impacted by memory loss, by:

- focusing first on the person, and then the impact of memory loss;
- providing supportive, positive ways to increase meaningful living;
- recognizing that every person living with dementia has a unique journey;
- endorsing community engagement in music through choral singing; and
- fostering joy and meaning for persons living with dementia.

Having a disease that causes dementia does not dictate the end of meaningful living. When we recognize our own unexplored biases, we open new doors of possibility. Through these choruses, opportunities



Resounding Voices Chorus singers in Rochester, MN and Stewartville High School Chamber Chorus singers share a collaborative intergenerational performance.



Members of the *Giving Voice Chorus* in Minneapolis.

for creativity and joy are available to enrich quality of life. They are a bright light for everyone—singers, family members, and audiences. All are touched by the music.

For more information and to view videos of the choruses, please visit these resources:

Giving Voice Initiative. Questions and contact information: <https://givingvoicechorus.org/> CBS News broadcast: <https://www.cbsnews.com/video/how-a-unique-chorus-group-is-giving-a-voice-to-people-with-alzheimers/#x>; worldwide chorus locations: <https://givingvoicechorus.org/join-a-chorus/>

Resounding Voices Chorus. Contact information: <https://www.resoundingvoices.org/>; Video: https://www.resoundingvoices.org/https://youtu.be/sBF_2YKkEH8/

Centro Wise Elders Chorus. Contact information: <https://www.centromn.org/wise-elders>; Video: <https://vimeo.com/581638583/>

Amazing Grace Chorus. <https://www.mprnews.org/story/2021/11/15/st-paul-music-academy-to-expand-its-dementiafriendly-chorus>

REFERENCES

Aboseif, A., & Woo, B. K. P. (2020). Chapter 40—The stigma of dementia. In Colin R. Martin & Victor R. Preedy (Eds.), *Genetics, neurology, behavior, and diet in dementia* (pp. 633–645). Academic Press. <https://doi.org/10.1016/B978-0-12-815868-5.00040-2/>

Boyle, P. A., Buchman, A. S., Wilson, R. S., Yu, L., Schneider, J. A., & Bennett, D. A. (2012). Effect of purpose in life on the relation between Alzheimer disease pathologic

changes on cognitive function in advanced age. *Archives of General Psychiatry*, 69(5), 499–505. <https://doi.org/10.1001/archgenpsychiatry.2011.1487/>

National Institute on Aging. (2021). *What is dementia? Symptoms, types, and diagnosis*. <https://www.nia.nih.gov/health/what-is-dementia>

Sacks, O. (2008). *Musicophilia: Tales of music and the brain*. First Vintage Books Edition.

Disclosure. The authors have no relevant financial interest or affiliations with any commercial interests related to the subjects discussed within this article.

Funding. The author(s) received no specific grant or financial support for the research, authorship, and/or publication of this article.

Correspondence regarding this article should be directed to Barbara Greene at bgreene902@gmail.com



Barbara Greene, MPH, BA, (she/her), is a multicultural health care consultant and board member for *Giving Voice Initiative* in Minneapolis, Minnesota. Her specialties include healthy aging, hospice, and palliative care from a public health population-centered perspective. Her background in cultural anthropology and global health provides a foundation for her professional interests.



Marge Ostroushko, BA, (she/her), is the co-founder and managing producer of *Giving Voice Initiative*. She is a producer of National Public Radio award-winning programs including *A Prairie Home Companion*, *The Mississippi: River of Song* and *The Promised Land*. She developed new programs and expanded audience reach for Public Radio International for a decade. Her vision for the choruses stems from her mother's experiences with Alzheimer's disease.



Jodi Melius, RN, BS, (she/her), is a Nurse Study Coordinator at the Mayo Clinic Alzheimer's Disease Research Center in Rochester, Minnesota. She is a co-founder and former board member of the *Resounding Voices* chorus in Rochester. Jodi's work is in honor of her father, who lived with Lewy body dementia.