

Supporting Social Connection of People Living with Dementia



Introduction to Social Isolation and Loneliness

Social isolation and loneliness are increasingly recognized as critical and growing public health issues impacting the lives of millions of Americans. While social isolation and loneliness are related, they are different. Loneliness is defined as a subjective feeling of being alone or separated while social isolation is the lack of social contacts and having few people to interact with regularly.¹

In a May 2023 Surgeon General Advisory, United States Surgeon General Dr. Vivek Murthy warned about the public health crisis that loneliness, isolation, and disconnection pose to the American public. Prevalence of social isolation and loneliness in the U.S. now surpasses smoking (13 percent), diabetes (15 percent), and obesity (42 percent).^{2,3,4} These are significant issues for older adults and people with disabilities. Although individuals of all ages and backgrounds can be lonely and isolated, groups at higher risk include people with poor physical or mental health, people with disabilities, those experiencing financial insecurity, those who live alone, as well as single parents, older adults, and adolescents.⁵



Social engagement improves quality of life and people with strong connections experience better physical and mental health outcomes.⁶ In addition, when people are socially engaged in their communities, they provide important contributions to their communities through sharing their knowledge, talent, skills, experience, and wisdom with others.

Supporting Social Connection of People Living with Dementia

Dementia is the general term for loss of memory, language, problem-solving and other thinking abilities that are severe enough to interfere with daily life and activities.⁷ The most common form of dementia is Alzheimer's disease. Other forms of dementia include frontotemporal dementia, vascular dementia, and Lewy body dementia.



People living with dementia are at risk of experiencing social isolation and loneliness for reasons that include cognitive changes, relinquishing driving or lack of transportation, and changes in employment or volunteer status. Dementia can make it more difficult for someone to communicate, and it can also change how a person interacts and connects with others. A person living with dementia may have difficulty remembering conversations, have trouble following new activities, or fear the ongoing stigma that is associated with dementia. As a result, people living with dementia may withdraw from social activities or connections leading to social isolation and loneliness.

Friends, family, coworkers, and neighbors can feel uncomfortable or unfamiliar when learning how best to interact and communicate well with someone living with dementia, further contributing to the person's feeling of isolation and loneliness.

Remaining socially connected is vital for people living with dementia and their care partners because it supports quality of life and enhances health and

well-being. Social engagement programs focused on people living with dementia help to ensure meaningful, welcoming, and understanding connection opportunities.

Examples of Programs and Initiatives That Promote Social Connection

Building a safe and welcoming community environment that encourages social connection for people living with dementia is key. Below are examples of programs that encourage social connection for people living with dementia and can be replicated in communities across the country.

Memory Cafés

A memory café is a stigma-free social setting for people living with dementia and their care partners that provides both with an opportunity to connect with others who are on a similar journey in a welcoming, engaging, and supportive setting. Memory cafés can be held in a variety of venues including coffee houses, restaurants, libraries, museums, or community centers. Some memory cafés offer specialized experiences, such as intergenerational participants, hybrid, or virtual formats, or bilingual or non-English language cafés. For memory café resources, check out the Memory Cafe Percolator Network (www.jfcsboston.org), administered by Jewish Family and Children's Services.

- The Jewish Family and Children's Service (JF&CS) Memory Cafe in Boston, MA, features group art activities led by guest artists. University student volunteers and volunteers from the broader community join café participants



each month. Volunteers learn about dementia first-hand and bring this knowledge back to their peers, helping address the broader goal of reducing stigma around dementia at a community level.

Music Programs

Music is a powerful tool for people living with dementia that is shown to elicit memories and emotions.⁸ Studies show that music can also help to improve behavioral issues, such as agitation, of people living with dementia and promote connectedness with care partners.^{9, 10}

- The Giving Voice Chorus (givingvoicechorus.org) offers a model for dementia friendly choruses. A dementia-friendly chorus provides a social and creative outlet for people living with dementia to engage with others, often giving rise to new or deeper friendships. All participants—people living with dementia, care partners, and volunteers—benefit from participating in the opportunity. Singers participate in weekly rehearsals with a professional choral conductor who is trained to work with people living with dementia, with the experience culminating in a public performance.
- Music and Memory® (musicandmemory.org) is a nonprofit organization that emphasizes the therapeutic use of personalized music for people affected by a range of cognitive and physical conditions. A variety of organizations, as well as families and individuals, can benefit from Music and Memory, including aging service providers, adult day centers, and long-term care settings.

Art Programs

Similar to music programs, art programs can also enrich the lives of people living with dementia. It is increasingly recognized that participation in arts activities can contribute to the quality of life of people living with dementia by offering an emotional release and creative outlet.¹¹ In many instances, these programs also offer engagement or respite opportunities for care partners. Arts offerings can be an effective way to build social connections with others while alleviating the need to focus heavily on direct conversation.



- Opening Minds Through Art (OMA) (scrippsoma.org) is an evidence-based, intergenerational art program for people living with dementia that is headquartered at the Scripps Gerontology Center at Miami University in Oxford, OH. It provides participants with opportunities for creative self-expression and social engagement with other participants and the students involved in the program. The intergenerational aspects of the program also give younger generations of students the opportunity to improve their attitudes about aging.
- The Museum of Modern Art (MoMA) (moma.org) Alzheimer's Project, building upon the success of the MoMA's education programs for people living with dementia and their care partners, includes a variety of resources intended for use by arts and health professionals on how to make art accessible to people with dementia.

Evidence-Based Programs

The U.S. Administration for Community Living defines an evidence-based program as one that has: demonstrated effectiveness using experimental or quasi-experimental design, been published in a peer-reviewed journal, and been implemented in one or more community sites.¹² While there are various evidence-based programs suitable for people living with dementia or their care partners, Cognitive Stimulation Therapy specifically focuses on social engagement.

- The Cognitive Stimulation Therapy (CST) program is an evidence-based, non-pharmacologic group or individual intervention for people experiencing mild to moderate memory impairment. CST emphasizes making social connections, particularly with others experiencing memory loss. It provides an opportunity for social exchanges that participants may not have in their day-to-day lives, with a focus on reminiscence such as discussing events and experiences from the past. Each session begins with an introductory activity, group theme song and discussion of a current event and the themed main activity. Examples of themed activities include physical games, childhood experiences, number games, word association, and team quizzes. Each

session closes with suggested activities to complete at home. Find more information on the program website (slu.edu/medicine/internal-medicine/geriatric-medicine/aging-successfully/cognitive-stimulation-therapy.php).



- Additional evidence-based programs for people with dementia can be found on the Best Practice Caregiving database (benrose.org/best-practice-caregiving) on the Benjamin Rose Institute on Aging website. Developed in collaboration with the Family Caregiver Alliance and the Gerontological Society of America, the Best Practice Caregiving database offers providers detailed information on dozens of proven dementia caregiving programs.

Dementia Friendly Communities

A dementia-friendly community is a village, town, city, or county that is informed, safe, and respectful of individuals with dementia, their families, and care partners. By providing supportive options that foster quality of life of the person with dementia and the care partner, dementia-friendly communities help to ensure that people with dementia engage in their community and thrive in day-to-day living, helping to reduce potential isolation or loneliness.

- In the United States, Dementia Friendly America (DFA) (dfamerica.org) fosters a network of dementia-friendly communities. The DFA Community Toolkit guides communities through a research-informed process that fosters adoption of dementia-friendly practices across all parts of the community. DFA Sector Guides are also available that encompass and engage many stakeholders within the community and provide resources and actions each specific sector can take to be more dementia friendly.

Tips for Communicating with People Living with Dementia

Over time, people living with dementia may experience a gradual decline in their ability to communicate. People living with dementia may have trouble finding the right words, may lose a train of thought, rely more on gestures, or revert to a native language.¹³ As a result, family, friends, and others in the community may feel unfamiliar or even uncomfortable with how best to communicate with people living with dementia. Fortunately, there are many great resources with a variety of tips exist to support people as they learn to engage effectively with someone living with dementia.

- The **Alzheimer's Association** (alz.org/help-support/caregiving/daily-care/communications) offers communication tips, organized by whether someone is in the early, middle, or later stages of dementia. These straightforward tips include practices such as speaking to the person living with dementia rather than the care partner, engaging in a quiet space with minimal distractions, speaking slowly, and finding the meaning or the feeling behind statements instead of correcting.
- **Teepa Snow's Positive Approach to Care** (teepasnow.com) provides a wide variety of services to enhance awareness and increase dementia care skills with resources for professionals as well as friends and family.
- **Dementia Friends USA** (dementiafriendsusa.org) is part of a global movement that educates people about dementia. After attending a live session or watching online videos, Dementia Friends commit to an action, regardless of size, to support those who are impacted by dementia.

Connect and Learn on the Nationwide Network of Champions

To engage with others on this important topic, join the Commit to Connect Nationwide Network of Champions. Commit to Connect Champions are passionate leaders and innovators at the local, state, and national level dedicated to ending social isolation and loneliness. Champions work together to increase awareness of social isolation and loneliness, connect people who are at risk of social isolation to social connection programs and technologies and create more socially connected communities that are inclusive of all people including older adults, people with disabilities, and care partners. This network of peers supports collaboration through shared learnings and open communication across sectors and perspectives.



Join the conversation and become a **Commit to Connect Champion** (www.committotconnect.org/network-champions)!

Resources

- Alzheimer's Association: alz.org
- Alzheimer's Association Communication Tips: alz.org/help-support/caregiving/daily-care/communications
- Alzheimer's Disease Program Initiative (ADPI)- State and Community Grant Program: [acli.gov/grants](https://acli.org/grants)
- Alzheimer's Foundation of America: alzfdn.org
- Cognitive Stimulation Therapy: slu.edu/medicine/internal-medicine/geriatric-medicine/aging-successfully/cognitive-stimulation-therapy.php
- Dementia Friendly America: www.dfamerica.org
- Dementia Friends USA: dementiafriendsusa.org



- Eldercare Locator: eldercare.acl.gov
- Jewish Family & Children's Services Percolator Memory Café Toolkit: jfcsboston.org
- Giving Voice Chorus: givingvoicechorus.org
- Museum of Modern Art Alzheimer's Project: moma.org/visit/accessibility/meetme/practice
- Music and Memory: musicandmemory.org
- National Resource Center for Engaging Older Adults (engAGED): <https://www.engagingolderadults.org>
- National Alzheimer's and Dementia Resource Center: <https://nadrc.acl.gov>
- Opening Minds Through Art (OMA): www.scrippsoma.org
- Teepa Snow Positive Approaches to Care: teepasnow.com

End Notes

- ¹ *Loneliness and Social isolation Linked to Serious Health Conditions*. (n.d.). Centers for Disease Control and Prevention. www.cdc.gov/aging/publications/features/lonely-older-adults.html
- ² *Current Cigarette Smoking Among Adults in the United States*. (2023, May 3). Centers for Disease Control and Prevention. www.cdc.gov/tobacco/data_statistics/fact_sheets/adult_data/cig_smoking/index.htm
- ³ *Prevalence of Both Diagnosed and Undiagnosed Diabetes* (n.d.). Centers for Disease Control and Prevention. www.cdc.gov/diabetes/data/statistics-report/diagnosed-undiagnosed-diabetes.html
- ⁴ *Obesity is a Common, Serious, and Costly Disease*. (2022, July 20). Centers for Disease Control and Prevention. www.cdc.gov/obesity/data/adult.html
- ⁵ Office of the Surgeon General. (2023). *Our Epidemic of Loneliness and Isolation: The U.S. Surgeon General's Advisory on the Healing Effects of Social Connection and Community*. www.hhs.gov/sites/default/files/surgeon-general-social-connection-advisory.pdf.
- ⁶ Office of the Surgeon General. (2023). *Our Epidemic of Loneliness and Isolation: The U.S. Surgeon General's Advisory on the Healing Effects of Social Connection and Community*. www.hhs.gov/sites/default/files/surgeon-general-social-connection-advisory.pdf.
- ⁷ *What is Dementia?* (n.d.). Alzheimer's Association. <https://www.alz.org/alzheimers-dementia/what-is-dementia>
- ⁸ Cmons, M. (2023, February 27). *Why Music Causes Memories to Flood Back*. Washington Post. www.washingtonpost.com/wellness/2023/02/26/songs-music-memory-connection/
- ⁹ *Art and Music*. (n.d.). Alzheimer's Association. www.alz.org/help-support/caregiving/daily-care/art-music
- ¹⁰ Bufalini, J., Eslinger, P. J., Lehman, E., & George, D. R. (2022). *Effects of a Personalized Music Intervention for Persons with Dementia and their Caregivers*. *Journal of Alzheimer's Disease Reports*, 6(1), 43–48. <https://doi.org/10.3233/adr-210043>
- ¹¹ Schneider J. (2018). *The Arts as a Medium for Care and Self-Care in Dementia: Arguments and Evidence*. *International journal of environmental research and public health*, 15(6), 1151. <https://doi.org/10.3390/ijerph15061151>
- ¹² *Health Promotion*. (2023, June 23). Administration for Community Living. <https://acl.gov/programs/health-wellness/disease-prevention>
- ¹³ *Communication and Alzheimer's*. (n.d.). Alzheimer's Association. www.alz.org/help-support/caregiving/daily-care/communications

Funding for this initiative was made possible by contract no. HHSP233201500088I from ACL. The views expressed do not necessarily reflect the official policies of the Department of Health and Human Services; nor does mention of trade names, commercial practices, or organizations imply endorsement by the U.S. Government.