

Age-Friendly Maple Grove: Dementia Grant Final Report

September 2021



Grant Overview:

[Trellis](#) awarded [Age-Friendly Maple Grove](#) (AF MG) a \$1,500 grant to conduct research about the current role and potential of faith communities in supporting people with dementia and their care partners. Major goals of the project were to 1) determine how AF MG can engage and support faith communities as they support members with dementia and who are caregivers, and 2) better understand how AF MG can make the community a better place for caregivers and people with dementia. The project ran from April through September 2021.

The two major elements of the grant were a **community member survey** and **faith community interviews**.

Community Survey:

- A nine-question survey focused on understanding where people with dementia and their care partners look for and receive support for challenges associated with the disease, and to what extent that might include faith communities.
- The survey was primarily administered online, promoted through various channels, and received 55 responses.

Faith Community Interviews:

- The Grant Action Team reached out to 31 faith communities in the Maple Grove area and successfully interviewed nine of them. This research was qualitative in nature.

Dementia Action Team Members

- **Patty Anderson**, Grant Action Team leader; small business owner
- **Mark Carpenter**, AF MG co-chair; Dementia Friends Champion
- **Elizabeth Faust**, City of Maple Grove; AF MG co-chair
- **Marie Maslowski**, RN, MPH
- **Lydia Morken**, **Morken Consulting**
- **Karen Nelson**, Adult Ministries Coordinator, Lord of Life Lutheran Church
- **Deb Stock**, Alzheimer's Association volunteer Community Educator and Caregiver Support Group facilitator
- **Kelly Swanson**, M Health Fairview Maple Grove

Several team members have or had family members with dementia.

Community Survey: Key Findings

- **55% of respondents indicated their experience with dementia involved a parent.** Only 10% indicated their experience involved a spouse.
- **34% identified as unpaid caregivers or helpers; 46% indicated that they were not caregivers.** Interestingly, 25% skipped this question. These responses may speak to the fact that many people engaged in less-intensive caregiving do not identify with the “caregiver” label. It may also be that a respondent is not currently a caregiver but was in the past.
- **90% said they were either comfortable (51%) or somewhat comfortable (39%) talking about their experience with dementia.** This was higher than anticipated but may indicate a couple of things.
 - First, that respondents were a self-selecting group of people already willing to share experiences related to dementia.
 - Second, people may be more willing than we think to talk about their experiences with dementia but may have few opportunities to do so because others avoid the topic.
- **Only 18% of respondents have looked to faith communities for information and support.** Faith communities are not a go-to resource for support related to dementia and caregiving. Most respondents turn to family (51%), then health care services and Alzheimer’s/dementia website (both 39%), neighbors (16%), and support groups or memory cafes (10%).
- **More than half of respondents (51%) skipped the question about which, if any, types of information and support they have received from a faith community.** This likely indicates that many people have not received support from a faith community, and/or that many are not actively connected to a faith community.
 - Five respondents indicated they have utilized caregiver support groups and/or respite care from a faith community
 - Six received home visits
 - Seven received dementia education for other members from a faith community.
- **48% said they would like to see their faith community offer dementia education to other community members.** Dementia education for community members ranked above caregiver support groups (37%), respite care (33%), and home visits (29%) as the most desired type of support respondents would like to receive from a faith community.

This likely speaks to the social disconnection and isolation that often accompanies dementia, as friends and acquaintances may be uncertain how to interact with the person with dementia, who simultaneously may experience shame or embarrassment.

Additionally, 51% of respondents skipped this question, likely indicating that they are not interested in receiving support from a faith community and/or are not actively connected to a faith community.

Faith Community Interviews: Key Findings and Observations

The Grant Action Team was able to interview nine of 31 faith communities in the Maple Grove area—about 29%. Team members reached out via email and phone and in many cases found it difficult to get responses. The nine with which we spoke represented a range of sizes, which was helpful in understanding the scope of experiences. Number of members ranged from 50 to 9,000, with the number of older adults active in each faith community ranging from 2 to 500.

Faith communities interviewed for this project:

1. Advent Lutheran
2. Christ's Community Moravian Church
3. Church of the Open Door
4. Cross Winds United Methodist Church
5. The Grove
6. Lord of Life Lutheran
7. Mosaic Church
8. Redeemer Lutheran Church
9. St. Vincent DePaul

Findings

- **Faith communities support their members through many challenges** at all life stages. They have few specific supports in place for dementia and caregiving but provide individualized support to members as needed.
- **Accessible buildings and services:** Many churches have made adaptations to their buildings and worship services that help people with dementia (and anyone who could benefit) participate more easily. Commonly noted items included:
 - Projectors/large screens at the front of the church
 - Buildings that are ADA compliant
 - Listening devices
 - Large print materials
 - Greeters to assist people who may need it (though no greeters are trained specifically in communicating with people with dementia).

Additional items included:

- Ear plugs for loud music
 - Sanctuary designed to be acoustically quiet to minimize bouncing of sound, which is helpful to people wearing hearing aids
-
- **The pandemic has impacted services and support;** some faith communities remain in transition, and most are trying to establish new practices going forward. Several noted that older members appreciated virtual services during COVID-19; some who did not offer virtual services prior to the pandemic may continue due to their popularity. Also noteworthy is the change in leadership at multiple churches due to retirements of pastors or other leaders. This also impacted their ability to participate in an interview.

 - **Respite care is too difficult to take on alone.** Many faith communities are aware of the need for respite care but noted significant barriers to being able to provide it themselves. Common challenges included staff capacity; training volunteers; availability of space and coordinating use of space with other building users; liability; and health regulations. Home visits are a less complex form of support that several churches offer and more said were willing to provide if requested. This input seems to indicate that an experienced partner who could take the lead in developing a respite program would be important.

 - **There is mixed interest in being involved in a larger dementia friendly communities faith community effort**—due largely to lack of staff and volunteer capacity or having other priorities.

 - **Multiple interviewees noted transportation as an important need for their older members,** both for Sunday services and on other days.

 - **Several have undertaken notable efforts related to older members:**
 - One faith community conducted a comprehensive spiritual assessment of members ages 55-plus (“Second Halfers”).
 - Some of the larger faith communities offer ongoing social and spiritual groups/programs for older members.
 - Prior to COVID-19, one started a collaboration with BeeHive Homes (a memory care community near the church) for visits and services.
 - Several mentioned “care teams” or similar—groups of volunteers who check in with, visit, and assist older members who need it.
 - Two of the nine have offered classes or workshops for staff/members related to dementia.

Observations:

- One key conclusion of the Action Team was that, to a large extent, **faith communities are self-contained universes**. They are primarily focused inward on their own members. This information helps us better understand what types of engagement are realistic to expect as well as to identify ways that AF MG can offer support.
- **The low response rate seemed due to several factors**, including the previous bullet as well as staff availability and capacity (including ongoing navigation of COVID-19); turnover of pastors/key staff; and potential financial stressors.
- **Interests of church leaders can determine the types and extent of dementia/caregiver support provided** by faith communities. In some cases, the departure of a pastor or other leader who had special interest in dementia and caregiving meant that certain services faded or ceased to be offered.
- **While important, this project does not reflect information related to experiences of various ethnic and cultural groups present in the Maple Grove area**. The Action Team's attempts to connect with diverse faith communities were unsuccessful. AF MG recognizes that engaging diverse communities often takes additional time and can be difficult without established relationships, which our Team did not have. We also understand that perceptions and norms related to dementia and caregiving vary considerably across cultures. We respect and value these differences and seek to better understand them as part of future work.
- **Words matter**. No single definition of "caregiver" exists, and not all cultures use or recognize the term. This complicates study of the topic because people identify (or not) as caregivers according to their own understanding of the word. Further, the terms "care partner" and "carer" also are now used, with most people not aware of the nuances of the nomenclature.

Potential Actions for Age-Friendly Maple Grove

Given what was learned through this project, we have identified the following roles and actions for AF MG in helping faith communities support their members who have dementia or are caregivers.

- **Offer support through education** by using the connections we have made through this work.
 - Provide information on local and area resources to faith community leaders to share with their members. Resources could include caregiver support groups, memory cafés, adult day, respite care, and others—including those programs offered through Maple Grove Parks and Recreation. Much of this information is already compiled on the AF MG website and could be easily shared online or in printed formats.
 - Provide training on how to be a friend to someone with dementia. This may be done using the Dementia Friends curriculum; AF MG’s team includes a Dementia Friends Champion who could lead some of the sessions.
 - Partner with a faith community who could host or provide space for an educational speaker or training. Some churches may even have funding available for speakers.
- **Explore promising respite programs** being offered at faith communities elsewhere in Minnesota or the U.S., and consider whether any might be appropriate for Maple Grove. Attempt to identify a local or area organization that might be a good candidate for a lead entity in co-creating/providing a respite program with a faith community. (For example, Allina Health has partnered with area churches to offer The Gathering, a popular group respite program.) There is a non-profit organization in Becker, Minnesota called Great River Faith In Action (grfia.org). They have a companionship program that offers respite to caregivers. AF MG could serve a facilitation role.
- **Use findings to help guide AF MG’s goals and strategies** for the next three-year action plan, which will be developed during 2022. Consider adding a dementia-specific team under the Community Support and Health Services subcommittee with members who are passionate and knowledgeable on this topic.

Age-Friendly Maple Grove would like to thank Trellis for the opportunity to complete this project.