



Advancing Dementia Friendly Community Initiatives in Georgia

A Final Report of Five Grant
Projects Awarded by the
Georgia Gerontology Society

June 2021

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I. Introduction

Led by the Dementia Friendly America (DFA) initiative, communities across the nation are taking action and becoming dementia friendly. A dementia friendly community is informed, safe, and respectful of individuals with dementia and their families and provides supportive options across the community to foster quality of life. DFA communities are working across sectors (such as with partners in health care, business and banking, legal and financial, faith communities, local government and more) to ensure they are friendly places for people with dementia and their caregivers to live. Every part of the community has a unique role in a dementia friendly community. DFA communities are building on a model developed by Minnesota's ACT on Alzheimer's and the dementia friendly communities in Minnesota. Dementia Friendly America is made possible by a national collaborative with over 35 national organizations. Dementia Friendly America is administered by the National Association of Area Agencies on Aging and was launched at the 2015 White House Conference on Aging.¹

In September of 2019, the Georgia Gerontology Society released a request for proposals to advance dementia friendly initiatives in Georgia by supporting community efforts in planning and implementing and phase of the Dementia Friendly Communities Toolkit. The toolkit guides communities through a research-informed process that fosters adoption of dementia friendly practices in all parts of community. The toolkit is designed to be flexible and adapt to fit a community's needs and complement other project management processes. The four phases are: Convene, Engage, Analyze, and Act.

Phase 1- Convene

Convene key community leaders and members to understand dementia and its implications for your community. Then, form an Action Team.

Phase 2 - Engage

Engage key leaders to assess current strengths and gaps in your community using a comprehensive engagement tool.

Phase 3 - Analyze

Analyze your community needs and determine the issues stakeholders are motivated to act on; then set community goals.

Phase 4 - Act

Act together to establish implementation plans for your goals and identify ways to measure progress.

You can find more information on the four phases at <https://www.dfamerica.org/community-toolkit-introduction>

¹ <https://www.dfamerica.org/>

In November 2019, five grants of \$2,000 were awarded to fund five organizations leading the dementia friendly effort in their communities:

- Caring Together in Hope/Amy's Place (Roswell, GA)
- Cobb Senior Services (Cobb County, GA)
- Legacy Link, Inc. (GA Mountains region)
- Three Rivers Regional Commission AAA (Heard County, GA)
- Valdosta State University/Alzheimer's Daycare Program (Valdosta, GA)

The grant cycle was originally planned for October 1, 2019 – September 30, 2020. However, due to COVID-19, the grant cycle was extended through April 30, 2021. Enclosed is a report from each grantee summarizing their efforts to help their communities become more dementia friendly. These grants were made possible through funds provided by the GA Department of Human Services, Division of Aging Services. If you would like to connect with the project managers for more information, please contact administrator@georgiagerontologysociety.org.

II. Caring Together in Hope/Amy's Place

Amy's Place experienced many challenges during the grant period. At the start of the grant, three individuals were available to work on the program. This was reduced to one and that individual was diagnosed with Breast Cancer. Amy's Place ultimately closed with the program manager taking the program with her to the Dementia Spotlight Foundation. The COVID-19 pandemic brought additional challenges to this project.

Despite these challenges, the project forged ahead with a narrowed scope of focusing on the immediate needs in the community instead of just rolling out meetings to introduce "Dementia Friendly Initiatives" and hoping people would participate.

The project was broken into two phases; the first was to gain some insight into some of the challenges and the second was to address the problems if possible.

Phase 1:

The project focused on gaining insight as to what were the biggest challenges that families faced when caring for someone living with dementia. This began with the families that visited Amy's Place as well as the people that call in asking for help. The results were:

1. There are not enough places in Georgia like Amy's Place that offer a place to socialize for care partners and those living with dementia.
2. Those that had paid caregivers wanted the caregiver to take their loved one out for a change of scenery and to engage with other people.
3. There are not enough programs for those that are in the early stages.
4. Care partners need a support group that will allow them to bring their loved one because many are not safe if left alone.
5. Going out in public was a real challenge and very stressful:
 - a. for the care partner and those living with dementia. For example, when eating out, restaurant staff may get annoyed with those that asked the same question over and over.

- b. Using the restroom could be problematic if there were no family restrooms available.
- c. Also, when shopping, many stores do not have dressing rooms specifically for both sexes, presenting the same challenges as the restroom situation.

Phase 2:

Taking the five findings in phase one, the project attempted to address solutions. Those five challenges provided a jumping-off point to start, and here are some of the things I did:

1. “Connection Café” began at Amy’s Place every Thursday from 12:00–4:00 pm. By designating these hours weekly, families could drop by, bring their lunch if they wanted and socialize with other families. A snack and drink are also provided. It began with a few people but grew to anywhere from 10-15 people throughout the day, with some of them making cookies at Amy’s Place or leading activities for the other attendees.
2. A “You & Me” Weekly Support Group began on Monday’s from 12:45–2:00 pm. This unique group experience offers two simultaneous circles; one for persons living with dementia, led by our new program coordinator, and the other for family, friends, or care partners. Since this is new, we’ve only had a few families participate, but we’ve received great feedback, and they continue to come.
3. We met with the Alzheimer’s Association’s Early Stage Program Manager to discuss collaborations to support those people in the early stage of dementia. Some ideas that are being considered include:
 - a. Holding a support group specifically for those in the early stage.
 - b. Provide an afternoon of games at least once a month for their Carpe Diem members.
 - c. Host a “Meet the Masters” program once the Alzheimer’s Association begins the program.
4. We are planning a Community Conversation dinner to introduce these concepts to our community.
5. We are widening our reach to include Alpharetta, GA.
6. We have recruited additional partners including an individual living with dementia, his care partner and a Care Coordinator.

When COVID-19 hit, Amy’s Place closed on March 11. This situation put a whole new spin on how we went about advancing this initiative and making a difference to all we serve. Since the majority of us were working from home, I decided to reach out to a few organizations to discuss how we could collaborate to help our families and continue to move the needle on my area becoming "Dementia Friendly.

1. We started having weekly “Zoom” meetings to support our families.
2. We produced activity packs individually designed to the person and had the caregivers either come by or it was mailed to them.
3. We sent out a survey to our newsletter subscribers asking about their technical capabilities to keep in contact—for example, private Facebook groups, Conference Calls by phone or video, or both.

4. Due to the social isolation of many of our families we instituted some porch parties, driveway parties and zoom parties so our families could feel they still had connections. Some of them included:
 - a. Sorbet drive by: Turned out people wanted to get out of their cars and talk to one and other with masks on.
 - b. Beatles birthday party: Attendees were handed out gloves with the saying “All you need is gLOVEs, sang beatles songs and had refreshments.
 - c. 90th virtual birthday party, we went to participants houses and handed them a box that had a cupcake, blowers and streamers, candy and surprised the birthday boy with a zoom birthday party where everyone sang Happy Birthday and presented virtual birthday cards they made.

As COVID rules changed, our people no longer felt comfortable to coming to the café for porch parties so we turned our attention back to activity packs that they could do in their home. Most of those were dropped off.
5. We have engaged additional community organizations. One of these organizations was Senior Services North Fulton. What they needed were ways they could communicate with the families by phone and activity packets to send to them. We produced packets of ‘conversation starters’, journal pages, and delivered 155 personalized activity bags for all their centers.

Since joining forces with Dementia Spotlight Foundation, we are moving forward with a concentration on “Memory Cafes”. We have several commitments from community partners to get these started.

III. Cobb Senior Services

Due to the COVID-19 pandemic, our original grant proposal plans had to be revised. We had several discussions with partners including a local dementia advocate, who runs dementia support groups with a local church, to brainstorm how to move forward and include persons living with dementia and their care partners. This advocate connected us with several care partners to assess their interest in dementia friendly initiative and to discuss the possibility of doing interviews to document their experience. While all these care partners had an incredible desire to share their story and help others, we realized we needed to revisit how to facilitate these interviews. We wanted to be sure we could lift-up their voices in a respectful way the individuals would be most comfortable (i.e., several expressed reservations with Facebook, in particular). It was also very important to us to find a way to share stories of persons who are living with dementia, not just care partners. After much consideration and in consultation with those most impacted by dementia, we determined the best method for beginning this dementia friendly process was to partner more directly with a local church, Due West United Methodist, who already had existing trusting relationships with these individuals.

In April 2021, a virtual conference, *Dementia Conversations with those who live with dementia and those who love them through it*, was hosted by Due West United Methodist Church in collaboration with Cobb Senior Services. This event featured presenters who are affected by dementia – both care partners and people living with dementia – and their lived experience. The

event included video interviews with people affected by and living with dementia, a live panel discussion, and performances by *Dementia Minds* – an advocacy group for people with dementia. This live event had 80 participants and afterwards, will be posted for others to view in the future.

The comments section allowed participants to interact and ask questions to the presenters. Several of the questions were about how to deal with a loved one with dementia when disoriented, or when a move is in order or how to seek help or take better care of yourself. Several of the comments were by care partners and people newly diagnosed themselves. All the presenters emphasized the importance on focusing on the strengths of people with dementia and what they can do rather than taking choices or activities away or treating them like a child.

The performances emphasized the fear, frustration and anger people living with dementia experience. There was an overarching theme of people in the community not understanding the disease, and several mentioned their dissatisfaction with health care professionals especially when first diagnosed. The performances dispelled stereotypes of people living with dementia as well as identified some fear and shame around dementia sometimes perpetuated in certain communities. One Black man living with dementia spoke about the lack of self-identification of a people living with dementia in the Black community even though they are disproportionately diagnosed with it. More awareness like this is needed by people living with dementia to create a more dementia friendly community.

With this grant funding, GGS has provided CSS the opportunity to support community efforts to begin the community change work outlined in Phase 1 of the Dementia Friendly toolkit during these unprecedented times of COVID-19. Our next step will be to work with individuals who participated in this event and other partners to assess the strengths and weaknesses of the community with dealing with dementia. We look forward of continuing this work for Cobb County in the future.

IV. Legacy Link, Inc.

Legacy Link's focus for the work on this grant was contacting almost forty faith-based organizations across the thirteen counties we serve in our North Georgia Mountain area, to recruit congregations into a round table style virtual discussion regarding dementia and church services. This task had a variety of successes and barriers that impacted our ability to convene these faith-based organizations. Our intern from the University of Georgia was given a list by the ADRC Director of local churches (2 to 3 in each of the 13 counties) to contact, explain the grant and our goals and build a professional relationship with.

We were successful in making contact 5 with local churches. We were able to secure a date of March 30th from 10 am to 12 pm to have our first virtual Dementia Friendly round table discussion. The discussion would focus on congregation reactions to people who come to church that have dementia and may display dementia behaviors. We also wanted to investigate the reasons why people in congregations stop coming to services and church functional all together because they have dementia behaviors. We also included the feelings and experiences of the caregivers and spouses as well.

We got an RSVP from two of our local churches for the March 30th session. Handouts, survey and return address envelopes were mailed direct to the recipients (expected 25-50 people). An email with the zoom link was sent out by the Legacy Link Intern a week ahead of time. An agenda was made to stick to the two-hour timeline for the session. The morning of, the ADRC Director and Legacy Link Intern waited 30 minutes before ending the session due to no one showing for the virtual session. We were disappointed to say the least.

We were able to reach out to another church that was local to us that had been referred to us by a fellow Legacy Link Employee. We contacted their Pastor, and we were able to secure a date of April 28th at 6:00 pm. They have a group of mixed older adults who meet every week on Wednesday at 6:00pm. The group included 16 participants. Some had caregiver experience, and some did not. Some were very active in the discussion and some just had a few things to add to the conversation. Once we got the roundtable position of the presentation going, we shared funny stories about loved ones we had cared for or just visited with. We also talked about why the group thought people stopped coming to church or church gatherings. Most of the response was due to embarrassment or the disease having progressed so far that the personal was no longer able get in and out of their home.

The church is small, and they did not seem to have had a whole lot of experience with their own congregation members dealing with dementia firsthand inside the actual church walls. I posed the question, “What would you all do if one of you in this group suddenly was faced with a dementia diagnosis and was embarrassed to come to church?” They all responded that they thought, if put in that situation, they would be supportive and caring. The hard part about this conversation with this particular church was that since COVID-19, they have been completely virtual and will remain so. With that said, there has not been any face to face visiting or services in 14 months.

We encountered some barriers that made it difficult to recruit participants into our virtual meetings. For many of the churches, we simply could not contact them at all – some churches had a telephone number no longer in service, some were wrong numbers, and for some we could only leave a voicemail or fill out an online contact form since no one would answer. This barrier, especially when the faith-based organizations would not answer entirely, could partially be attributed to the COVID-19 pandemic. This pandemic has caused many churches to go completely virtual, as well as possibly cut down on their staffed hours, which could make it difficult to contact them via phone.

Another barrier we encountered was a stigma surrounding dementia. Many churches had similar experiences of their congregation members receiving a recent dementia diagnosis, and they did not feel comfortable talking about it. Partially, this was because for some individuals their diagnosis was very new and recent, so they potentially were navigating the grieving process and were not comfortable talking about these topics. However, we did have some experiences of church clergy being afraid that their congregation members experiencing dementia may simply just not want to talk about the subject openly.

Additionally, we also had some difficulty with recruitment since the meetings were only going to be held virtually. Many of the faith-based organizations and their congregations were not

comfortable using Zoom, and some congregation members did not even have email addresses. This discomfort with virtual platforms excluded some of the faith-based organizations altogether. Also, some congregations simply did not want to participate in virtual settings, since they had a preference for in person events only.

We also experienced a few other miscellaneous barriers. Some congregations were experiencing a shift in their pastoral leadership, which made it an inconvenient time for scheduling any meetings. Some congregations simply did not have a lot of individuals that they knew of who were experiencing dementia, or who had loved ones who were experiencing dementia. Lastly, some churches just did not have openings in their schedule that would work with our availability at Legacy Link to schedule meetings.

Despite the various barriers in recruitment, we did have some successes and triumphs while working on this grant. Overall, we were able to schedule two round table discussions, however only one of those had participants show up to participate. However, in the one session that we were able to successfully hold, we experienced a large amount of open and productive discussion. The participants were able to share their experiences regarding their loved ones and their dementia diagnosis. The participants were able to express some of their struggles as well as share some commonly held experiences. We were able to explore some of the behaviors exhibited in those with dementia. Additionally, we were able to analyze the congregation's awareness and hospitality given to those experiencing dementia, as well as brainstorm any ways to make the environment and congregation as a whole could be more welcoming and accepting of those with dementia. Overall, this round table meeting was successful and allowed members of the faith-based organization to convene and discuss their personal experiences and the status of the congregation's hospitality and awareness on the subject of dementia.

V. Three Rivers Regional Commission AAA

In June 2020, Three Rivers RC AAA held a Dementia Friendly meeting with nine in attendance. This was the first virtual Dementia Friendly meeting due to the COVID-19 pandemic. The group revisited the original plan of holding a Care Fair in June. The group is currently in between the Analyze and Act phases. The group brainstormed ideas and strategies moving forward due to the pandemic. Strategies are as follows:

- An article will be written to ask Heard County citizens to identify caregivers and those living with dementia and ask that they reach out to Three Rivers RC AAA. The goal will be to mail a survey to the individual that they will complete and mail back. The survey will help identify their specific needs. As an incentive, those who send information back in will be in the drawing to win a \$50 gas/grocery card.
- Survey results will be compiled to identify additional Heard County needs.
- A flyer will be created to distribute to the community. It will provide basic information about our Dementia Friendly Group.

Other possible needs include:

- Providing transportation for COVID testing

- Running errands for caregiver
- Financial assistance due to COVID
- Temporary in-home services (cooking, cleaning, laundry, grocery shopping, meal prep)

The next meeting was held on in August of 2020 with ten in attendance. An overview of federal funding received by Three Rivers in response to the pandemic was provided. The Families First Coronavirus Response Act provided \$393,474 for emergency meals going through September 2021. These meals will be provided to home delivered and congregate (senior center) participants. The Cares Act funding in the amount of \$1,268,323 will go towards providing additional meals during the pandemic as well as supportive services (in home services, home modifications, transportation, material aid, etc.) and caregiver services. In addition, \$50,250 will be provided to the Aging and Disability Resource Connection and Three Rivers will provide the following services with this money: telephone reassurance, transportation vouchers, emergency packets, and behavioral health coaching.

An update was provided for the questionnaires and flyers that had been distributed. Several individuals called/emailed and surveys were sent to those individuals. The Heard County Senior Center distributed the surveys to all home delivered meal clients and those surveys have been returned. An article was placed in the online paper and newspaper. Surveys were due back in August 2020.

The group also discussed printing cards that read, “The person I am with has dementia, please be patient, thank you.” The group can include the Three Rivers logo and the title of Dementia Friendly Heard on the cards.

In December of 2020, the third meeting was held with nine in attendance. The group decided to use remaining grant funds to provide respite, transportation, and emergency packets to caregivers and those living with dementia.

In January of 2021, Three Rivers RC AAA provided the Dementia Friends Champion training to members of the Dementia Friendly Heard group with six in attendance. The training will be provided twice so that less individuals will be in one room at a time to adhere to social distancing.

In April of 2021, Three Rivers RC AAA provided the second Dementia Friends training to seven members of the Dementia Friendly Heard team. There was a lot of feedback and interaction in the meeting. In addition, after the meeting, one of the attendees who is a pastor asked if the training could be conducted with his congregation. Plans are to provide the training in June 2021.

In April of 2021, Three Rivers RC AAA reached out to the only nursing home in the county to identify individuals living with dementia in the nursing home. The social worker indicated that approximately 10 individuals live with dementia. Three Rivers RC AAA asked the social worker to provide a list of assistive technology items/devices for which the individuals could use. The remaining grant funds were spent on assistive devices consisting of weighted blankets, stuffed dogs and cats, fidget devices, and activity books.

Our Dementia Friendly Heard team plans to continue to meet even though the grant period will be ending. Though the pandemic has slowed down some efforts, we have been resilient and identified activities that could be completed during this trying time.

VI. Valdosta State University/Alzheimer's Daycare Program

“My Friend’s House” was fortunate enough to receive a \$2,000.00 grant from Georgia Gerontology Society, Inc. in 2020 in order to help churches and businesses to become aware of the issue regarding dementia, and to help them to become a part of the dementia-friendly initiative.

The original idea was to have a dinner and invite community partners to participate and to provide them with educational information regarding the issues that families are facing when their loved one(s) may be suffering with dementia. Our initiative was appropriately named “Compassionate Lovegivers Initiative” which displays a compassion which is needed for these individuals and families.

As a result of the COVID-19 pandemic, the original plans which we had for using the funds had to be revised. We originally decided to send a monthly informational newsletter to the agencies, especially churches. The first newsletter was sent in March 2021.

Additionally, we purchased 250 Dementia Friendly Community t-shirts which will be distributed to teams that will be recruited for a Community Health Fair focusing on senior issues, including dementia.

We appreciate the opportunity of being able to make our community more aware of this dread disease of dementia that so many of our families are facing. Community outreach and education has been an integral part of our program, and we hope to continue to make families aware of the help and resources which are available to them.

VII. Conclusion

The Georgia Gerontology Society is proud to have been able to award funds to advance dementia friendly initiatives in five communities. Working towards becoming dementia friendly varies from community to community. Amongst our grantees, there was diversity in the way each community tackled this challenge with some having more success in completing phases of the toolkit than others. The COVID-19 definitely provided many challenges. The grantee organizations as their community partners were unable to focus on new initiative towards the beginning of the pandemic. As with all organizations, determining how to safely provide services to clients took priority. Despite these challenges, all of the grantees made strides towards implementing dementia friendly initiatives in their communities with all continuing this work after their grants have ended. GGS would like to thank the GA Department of Human Services, Division of Aging Services for making these grants possible and allowing GGS to be a catalyst for making Georgia more dementia friendly one community at a time.