A Look at Affordable Telephone Support Programs for People with Dementia and Caregivers

Presented by:
Cliff Burt, MPA, Aging Services Coordinator, Georgia Division of Aging Services
Linda Harris, MPA, HCBS Case Manager, River Valley Area Agency on Aging
Kristi Fuller, MSW, Senior Research Associate, Georgia Health Policy Center, GSU
Lucretia Smith, LPC, Helpline Support Manager, Alzheimer’s Association GA Chapter
Suzette Binford, M.Ed., Atlanta Programs Director, Alzheimer’s Association GA Chapter
Telephone Reassurance Programs: An Overview

• Telephone reassurance programs have been done for decades for people with a wide variety of needs
  – Seniors
  – People with disabilities
  – People with other special needs/issues

• Telephone reassurance for people with dementia and caregivers is newer

• The Georgia Division of Aging Services and the Alzheimer’s Association, GA Chapter looked at models for these programs as we began to focus on being more dementia capable as a state
  – The National Alzheimer's Association’s peer support telephone program for people with early stage dementia had been shown to be very successful
Origins of Georgia’s Telephone Reassurance Programs for People with Dementia and Caregivers

• Through a demonstration grant on early stage dementia, in June 2011, DAS convened a meeting of stakeholders: AAAs, APS, Alzheimer’s Association, HCBS and CCSP staff
  – Concensus: telephone reassurance would be an effective way to serve and support clients on waiting lists and those with dementia who live alone

• July 2011—DAS applied for an ADSSP (Alzheimer’s Disease and Support Services) grant, the purpose of which is to increase the state’s dementia capability. The AoA required statewide interventions, so DAS partnered with the Alzheimer’s Association on the Telephone Reassurance initiative.
Georgia’s Telephone Reassurance Programs cont.

• It was decided that two telephone reassurance models would be implemented:
  – Centralized model—volunteers come in to one location to make calls; adopted by Alzheimer’s Association. (Referrals solicited from 11 AAAs statewide.)
  – Decentralized model—volunteers make calls from home; adopted by River Valley AAA. (Service provided for River Valley Region only.)

• DAS contracted with GSU’s Health Policy Center to evaluate the centralized model
  – Decrease in funding did not allow for evaluation of the decentralized model
  – Fewer evaluations of the centralized model have been done, making the data more valuable

• To build sustainability of the program, the grant called for a statewide training to be held on both models.
Heart to Heart - H₂H

• Peer to Peer Telephone Support Program
• Targets clients who live alone and/or little or no caregiver support
• Caregivers and persons diagnosed with Dementia
• Volunteers and participants taken from HCBS client waiting lists
Program Inception

- Developed 11/2009 (research, proposal)
- Initially developed for social networking
- Approved by Director- 01/2010
- Piloted Muscogee County- 10 participants
- Initial surveys conducted (9 interested)
- Follow-Up Surveys (positive)
- Additional Counties- (check area codes/long distance)
Program Goals

• Promote Safety
• Decrease Social Isolation & Loneliness
• Provide Client & Family with a Sense of Well-being
• Share Resource Information
Implementation

• Program Coordinator
• Administration
• Volunteer Recruitment/Training
• Participant Recruitment
• Maintain Files
• Program Evaluation
Administration

- Forms - Letter, Privacy Rules, Participation Agreement, Call logs
- Reporting - monthly, mail SASE
- Maintain files
- Surveys
Volunteers

- Volunteers from Waiting lists (Low DONR’s)
- Check DON-Rs (telephone, HOH, vision impairments, or anything that could hinder ability to participate)
- Build rapport/Discuss program
- Allow volunteers to choose number of participants
- Contact Participants (Initial Call by Program Coordinator)
- Volunteer Training (Packet-Documentation, Emergencies, Reporting)
- Encouragement/Volunteer Retention is key)
Program Updates

• Volunteer resource booklet - Taken from Database
• Community Volunteer Coordinator
• FY 2015 - 2 additional rural counties; 15 additional participants
“Most of the seniors are dealing with several physical illnesses. Some seniors are faced with the loss of mobility and independence. Many of them are lonely. I worry about them. I always listen for a smile in their voice. As the lyrics in a Michael Jackson song go, the Heart to Heart program is letting the seniors know ‘you are not alone.’”
“She calls me all the time. I enjoy having conversations with her.”
For More Information Contact:

Linda Harris, Program Coordinator
River Valley Regional Commission
Area Agency on Aging
706-256-2939
lharris@rivervalleyrcaaa.org
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Ginny Helms, VP of Programs and Public Policy, Alzheimer’s Association GA Chapter
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A Time To Talk
Telephone Reassurance Program

• Background: increased focus on people with early stage dementia

• Special issues of people with early stage:
  – Emotional issues
  – Lifestyle issues
  – Practical coping issues

• Telephone reassurance program provides benefits for people with early stage in two ways
  – Those who are being called receive support, reassurance, and care
  – Those who are making calls feel that they have a purpose, and are useful and helpful to others

• Based on St. Louis Chapter’s Peer Support Program, but we added the component of caregivers calling other caregivers
Program Goals

• Promote safety
• Increase support for persons with early stage dementia and care partners
• Decrease social isolation and loneliness
• Provide client and family with a sense of well-being
• Share resource information
Implementation

• Program Coordinator
• Administration
• Volunteer Recruitment/Training
• Participant Recruitment
• Conducting Calls
• Documentation/Maintaining Files
• Program Evaluation
Administration

- Forms - letter, privacy rules, participation agreement, call logs
- Marketing the program
- Reporting - monthly
- Maintaining files
- Program evaluation surveys
Volunteers

• Diagnosis of early stage dementia OR have self-reported memory loss
• Volunteer Training (Manual—confidentiality, resources, boundaries, documentation, emergencies/crisis situations, reporting)
• Build rapport/discuss program
• Allow volunteers to choose number of participants
• Contact participants (initial call by program coordinator)
• Volunteer Retention
Results

- Number of people served by end of grant:
  - 51 participants (persons receiving calls)
    - 30 caregivers
    - 21 persons with dementia
  - 12 volunteers
    - 7 caregivers
    - 5 persons with dementia
Lessons Learned

• Volunteers have the option of making calls from home after demonstrating competency
• More volunteers needed statewide to reach more people
• Volunteer and participant matching
• Secondary contact for all program participants
• Program coordinator meet quarterly with volunteers to discuss program
• Overall: volunteers and participants both benefitted: shared similar experiences, engaged in meaningful discussions
Evaluation of the
A Time To Talk Program

Kristi Fuller, MSW
Georgia Health Policy Center
Evaluation Components

• Interviews with:
  – Participants who are Persons with Dementia
  – Participants who are Caregivers
  – Program Volunteers
  – The Program Coordinator
Persons with Dementia

• Seven participants agreed to participate in the interview, representing 58 percent of the participants eligible for an interview as of September 2013.

• Of the remaining participants, two could not be reached, one declined to participate, and two were unable to complete the survey due to either a lack of current participation or inability to recall participation in the program.
Persons with Dementia

- The participants represented three of DAS’ Planning and Service Areas: the Atlanta Regional Commission (n=5), Northwest Georgia Regional Commission (n=1), and the Central Savannah River Regional Commission (n=1).
- Six of the participants were female and one was male.
- All of the participants were over the age of 60.
- One participant indicated veteran status.
Persons with Dementia Participants’ Location

- Rural: 14%
- Urban: 86%
Persons with Dementia Participants’ Race

- White or Caucasian: 71%
- Black or African-American: 29%
Summary of Findings

• The program participants with early stage dementia had some difficulty remembering the calls with the volunteers, or differentiating A Time to Talk from other programs they were participating in.

• Participants expressed an interest in the program due to having the opportunity to talk with peers who they could relate to. One participant stated “[I] wanted to hear from someone in the same place I was, not experts.”

• All of the participants felt that the volunteers were reliable.

• One of the participants felt that they did not currently have a good match, and thus the program may need to seek feedback from the participants to re-match to a different volunteer if necessary.

• The participants reported that they liked the volunteers, felt that they could trust the volunteers, and appreciated being able to participate in the program over the phone.
Caregivers

- Eleven participants agreed to participate in the interview, representing 55 percent of the participants eligible for an interview as of September 2013.
- Of the remaining participants, four could not be reached, two did not participate because the person they were caring for passed away, two stated that they were not currently participating in the program, and one could not participate due to a decline in mental health.
Caregivers

• The majority of the participants reported that they were primarily providing care for a spouse (n=6). Two participants were providing care for a parent, one was providing care for another relative, and one did not report for whom they were providing care.

• The participants represented five of DAS’ Planning and Service Areas: the Atlanta Regional Commission (n=7), Northeast Georgia (n=1), Northwest Georgia (n=1), Legacy Link (n=1), and the Central Savannah River Regional Commission (n=1).

• Ten of the participants were female and one was male.

• Nine of the participants were over the age of 60, and two were under 60.

• One participant indicated veteran status.
Caregiver Participants’ Location

- Rural: 64%
- Urban: 36%
Caregiver Participants’ Race

55% White or Caucasian
45% Black or African-American
Summary of Findings

- The program participants who are caregivers described seeking support based on their role and the challenges of providing care to a loved one.
- The opportunity to speak with, and learn from, a peer was also an important reason for participating.
- All of the participants felt that the volunteers had been reliable in contacting them and that they provided follow-up when needed.
- Some of the participants reported talking with volunteers about things that they had not discussed with other family and friends, providing a valuable outlet for the caregivers.
What Did You Like Best About the Program?

• “Mostly that someone is there and that they care.”
• “I have friends but if you never had the problem, you don’t know what a caregiver is going through. She knows what I’m going through.”
• “Having an opportunity to talk to somebody.”
• “Having someone to call me. Talking about it is a wonderful outlet. Volunteers understand if it is a bad time to talk.”
• “Being able to have some support other than family/friends. [They are] able to be more objective with what you are dealing with at that time.”
• “Not hearing about other’s history or experiences.” [Like what happens when you talk with people in the community and they begin telling you what they are dealing with]
• “They didn’t forget about me.”
• “It helps to know you are not alone.”
• “The volunteer—he is passionate, energetic, and supportive. He has given concrete suggestions too.”
Volunteers

• The interviews were conducted by telephone utilizing a semi-structured interview guide between September 9, 2013 and September 19, 2013.

• Five volunteers agreed to participate in the interview, which represented the current volunteer pool for the program.

• Two of the volunteers had early stage dementia and three were caregivers.

• Four out of the five volunteers were male.
Summary of Findings

• The current volunteers reported feeling adequately trained with regard to their roles, and all felt that the support provided by the Alzheimer’s Association was sufficient and enabled them to feel more comfortable.

• The seriousness of the topics discussed was acknowledged by one volunteer, and the need for this type of support was discussed by several individuals. One volunteer expressed this feeling when he said, “Knowing you’ve reached out and helped them is very positive. [There are] a lot of opportunities to feel rewarded from participation.”

• Several of the volunteers mentioned that they often had difficulty reaching the participants, which was frustrating at times.

• One volunteer felt that her ability to convey to the caregivers that, “I’ve been there, done that, and survived” is valuable for participants and also for her.
Program Coordinator

- The program coordinator was invited to complete an interview to provide information on her experience implementing and managing the A Time to Talk program.
- The interview was conducted by telephone utilizing a semi-structured interview guide on September 3, 2013.
Summary Of Findings

• Program Implementation
• Challenges: recruitment/retention of volunteers, travel to the office, managing contacts
• Suggestions: in-person volunteer team meetings, allowing volunteers to make calls from home, recruitment of volunteers from across the state, requesting that volunteers give a month notice if they are unable to continue making calls, and collecting secondary contact information from participants
For more information:
Kristi Fuller: kwfuller@gsu.edu
Questions?