

Alzheimer's Association, Georgia Chapter
Telephone Reassurance Program

**Manual on How to Implement a Telephone Support Program for Persons with Early Stage
Dementia and Caregivers**

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Table of Contents

Program Background

- How the Program Originated
- Purpose of Manual
- Contact Information about the Manual

Telephone Reassurance Program

- About Telephone Reassurance
- Goals of the Program

Implementation

- Getting Started
- Recruiting Volunteers
- Training Volunteers
- Retaining Volunteers
- Recruiting Participants
- Enrolling/Disenrolling Participants
- Conducting Phone Calls
- Emergency Procedures
- Record Keeping

Program Evaluation

- Follow up interviews
- Discharge evaluation

Program Background

How the Program Originated

In June of 2011, a work team meeting was held at Calloway Gardens. Representatives from the twelve Area Agencies on Aging, Adult Protective Services, Medicaid waiver programs, the Alzheimer's Association, and the Georgia Division of Aging Services were present. Discussions were held on how to better serve persons with early stage dementia and their caregivers. Many representatives expressed that long waiting lists hindered the ability for individuals to obtain services. The Director of the River Valley AAA reported implementing telephone support for individuals on their waiting list. They used people with low DON-R scores on the waiting list to serve as volunteers in making support calls to others. From this came the idea of implementing a peer telephone support program for caregivers and persons with early stage dementia, which would utilize volunteers to place calls to participants.

Purpose of this Manual

The purpose of this manual is to meet one of the requirements of the grant in composing a how to manual for others to have the ability to duplicate the program. It will serve as a guide to the twelve Area Agencies on Agency in implementing a telephone support program.

Contact information about the Manual

For additional information on this manual, please contact Camille Noell, Helpline Support Manager, at the Alzheimer's Association via e-mail cnoell@alz.org or by phone at (404)728-1181.

Telephone Reassurance Program

About Telephone Reassurance

Telephone Reassurance is a one on one peer telephone support program. Persons with early memory loss provide telephone calls to persons with early stage dementia. Present or past caregivers provide telephone calls to current caregivers. Callers and participants connect through similar situations and experiences. Callers provide emotional support, share coping strategies, and offer a listening ear to participants.

Goals of the Program

There are three objectives for the program, which are as follows:

1. Increase support for persons with early stage dementia and caregivers of persons with dementia by developing and implementing a statewide financially viable and sustainable volunteer based telephone support system.
2. Increase access for persons with early stage dementia and caregivers to the telephone support system by developing and implementing a physician referral program.
3. Increase the availability of telephone support programs by offering training to the twelve Area Agencies on Aging in Georgia.

Implementation

Getting Started

In preparing for the program to begin, a Program Coordinator will need to be designated. It is important for the Program Coordinator to be qualified to recruit and manage volunteers, provide direction in difficult situations, maintain files, market program, and recruit participants. In managing early stage volunteers, the Program Coordinator will have to oversee phone calls more closely to ensure there are no inappropriate conversations or that no documentation is forgotten. The Program Coordinator should also watch for and assess the ability of the volunteer to continue making phone calls when there is a progression of the decline in the person's memory.

An appropriate area will need to be designated for volunteers to conduct phone calls. The area should be easily accessible to the Program Coordinator yet private enough for volunteers to talk freely without worrying about disrupting others or breaching confidentiality. The area should be equipped with a phone, pen and paper for taking notes, a desk for writing, and a chair. The area should also have any important reminders posted to assist the volunteer in remembering what he/she needs to do. You may also want to consider other optional things such as providing candies and/or water which will make the area more welcoming and comfortable for the volunteer.

Recruiting Volunteers

The Program Coordinator for the program should explore several different avenues for recruiting appropriate volunteers. Potential volunteers could be recruited from agency callers,

support groups, programs for persons with early stage dementia, volunteer websites, physician's offices, case management programs, and in-home providers. The Alzheimer's Association has been most successful in recruiting volunteers from its early stage programs and posting the opportunity on volunteermatch.org. The Program Coordinator will need to contact potential volunteers who are interested in assisting to discuss the program, answer any question, and assess the ability of the volunteer. To be eligible to volunteer, early stage dementia volunteers must be diagnosed with Early Stage Dementia or have self-reported memory loss. Caregivers must have past or present experience caring for a person with dementia. The potential volunteer must also be willing to submit to a background check, attend a training session prior to starting, and agree to the terms of the confidentiality policy. It would also be beneficial if the volunteer resides close to the office as the volunteer will need to be able to travel to the office to conduct phone calls.

Volunteer Training

Prior to placing phone calls, all volunteers should sign a confidentiality agreement, submit to a background check, and attend a training session. Volunteers are not expected to have direct contact with participants. If direct care becomes necessary at some point, then a volunteer should also submit to a fingerprint record check prior to providing direct care.

During the training session, volunteers should be provided with a training manual for reference and trained in the following areas:

Overview of resources available

Goal of the program

Expectations and roll of the volunteer

Conducting Phone Calls

Boundaries – when to advise a participant and when to make a referral

Documentation – how to fill out contact and critical incident forms

Keeping information confidential

Telephone Etiquette

Emergency Procedures

Retaining Volunteers

Regular volunteers are important to participants in establishing relationships and trust in the volunteer. It also important to the Program Coordinator whereas recruiting and training new volunteers is costly and time consuming. There are several ways to ensure the commitment of volunteers. Ultimately, volunteers want to feel welcome and valued. So, the volunteer area

should be inviting and close to the Program Coordinator for easy access to support if needed. The Alzheimer's Association has set up two cubicles adjacent to the Program Coordinator. In addition to easy access to the Program Coordinator, volunteers have access to drinks and candy to make them feel more at home. Regular communication and recognition from the Program Coordinator will make the volunteers feel valued. The Alzheimer's Association provides regular volunteer appreciation quarterly with a personalized thank you note and a small gift.

Recruiting Participants

The Program Coordinator should explore many different options for recruiting participants. Potential participants could be recruited from agency callers, support groups, programs for persons with early stage dementia, physician's offices, case management programs, and in-home providers. The participants must either be a current caregiver for a person with dementia or diagnosed with early stage dementia. Most referrals to the Alzheimer's Association program come from Helpline calls. The Program Coordinator is responsible for contacting potential participants to discuss the program and answer any questions. Once a participant has decided to enroll, the Program Coordinator will assign a volunteer to the participant for twice a month telephone calls

Enrolling/Disenrolling Participants

New participants will be referred to the Program Coordinator for enrollment. The Program Coordinator will complete a participant information sheet and set up a new file. The information sheet will include a participant's name, DOB, address, phone numbers, e-mail address, emergency contact, referral source, and best times to call. New participants will be assigned to a volunteer and placed on a volunteer's master call list. The Program Coordinator will also send the new participant a welcome letter containing contact information for the program and information on the evaluation process.

Participants who request to be disenrolled from the program will also be referred to the Program Coordinator who will remove the participant from a volunteer's master call list. The Program Coordinator will document the date of disenrollment and reason on the participant information sheet. The Program Coordinator may make changes to improve the quality of the program based on the response of the former participant.

Participants who are unable to be reached and do not respond to messages can also be discharged. If a participant is unable to be reached for two consecutive months, then a letter should be sent to the participant by the Program Coordinator. The letter should request the

participant contact the Program Coordinator to continue in the program. Upon sending the letter, the Program Coordinator should give ample time for the participant to respond. If there is no response after two weeks, then the Program Coordinator should disenroll the participant.

Conducting Phone Calls

The Program Coordinator should maintain a consistent call schedule for each volunteer to ensure adequate volunteer space and expected call times for the participants. Volunteers with early memory loss and caregivers will report to the office to conduct phone calls. Upon arriving to the office, volunteers will check in with the Program Coordinator and obtain their master list of participants to be called. Each volunteer will have their own list in order to limit access to other participant information. The volunteer will pull the files of each participant to be called. The file will contain the participant information sheet. The file will also contain past contact reporting forms and incident reports for the volunteer's review.

Volunteers will contact a participant two times per month to provide support and coping strategies. A volunteer with early memory loss will call up to three participants with early stage dementia. A caregiver volunteer will call up to five participants. Whenever possible, the same volunteer will contact the same participant. If the participant needs further assistance, then a volunteer will refer the participant to the appropriate program. If the volunteer is unsure where to refer the participant to, then the volunteer will consult with the Program Coordinator.

At the completion of each phone call, the volunteer will complete a contact reporting form. When a volunteer is made aware of a critical incident, then he/she will also complete a critical incident report with the assistance of the Program Coordinator. The volunteer and program coordinator will come up with a plan for preventing or responding to the incident. Forms will be filed in the participant's record by the volunteer.

Upon completing all phone calls, volunteers will replace the participant files in the filing cabinet. The files will be maintained in alphabetical order and reviewed monthly by the Program Coordinator.

Emergency Procedure

In case of a reported emergency, a volunteer will call 911 to ensure a participant receives the required assistance. An emergency is any situation that requires immediate assistance from medical, police, or fire services. The volunteer will notify the Program Coordinator and

complete a critical incident report. The volunteer will also follow up with the participant on the next scheduled telephone call to see if further assistance is needed.

Record Keeping

Each participant will have an individual file to limit access of other participant information. Files will be kept in a locked cabinet next to the Program Coordinator's office area. Filing drawers will be labeled either "active" or "inactive". Active drawers will contain all of the current participant files. Inactive drawers will contain all of the former participant files. All files will be kept in alphabetical order. Files will be kept for 6 years following disenrollment. All information to be discarded will be shredded.

Program Evaluation

Follow up interviews

Program participants will be called for an interview after they have been enrolled in the program for six months. Interview questions have been constructed through 1) a review of the St. Louis program that served as a model for the Georgia program, 2) a review of the Georgia program operational protocol, program description, flyer, and 3) an interview with the Telephone Reassurance program manager that focused on the goals, objectives, and evaluation questions. The interview guides have been reviewed by Alzheimer's Association (AA) program staff and Division of Aging staff. The interview is optional to the participant.

Discharge evaluation

The Program Coordinator will discuss with the participant why he/she wants to disenroll. The Program Coordinator will document the date of disenrollment and reason on the participant information sheet. The Program Coordinator may make changes to improve the quality of the program based on the response of the former participant.



A Time to Talk Follow-Up Interview

ID: _____

Date: _____

Interviewer: _____

We are going to ask you some questions regarding your experience with A Time to Talk over the last six months. *(Some or all of the following questions may be asked)*

1. Please tell me what interested you in the Time to Talk program.

2. Was the program what you expected? If so, how? If not, could you help me understand why it was different than what you expected it to be?

3. Can you tell me a bit about the person who called you?

4. Do you think the volunteer was a good match for you? Why or why not?

5. Was he/she reliable?

6. Did your call partner give you ideas for how to cope with any issue(s) or challenges you were having?

7. Did you have questions that that he/she couldn't answer?

8. Did you talk about things that you haven't talked about with other family or friends? If yes, would you feel comfortable telling me what kinds of things?

9. Are there things that you would like to talk about, but felt that you couldn't as part of this program? If yes, would you feel comfortable telling me what kinds of things?

10. What did you like best about the program?

11. Are there things about the program that you think could be better?

12. Would you recommend this program to others?

13. Can you describe your living situation?

14. Has this program changed how you feel about your current living situation? How about for your plans for living arrangements in the future?

15. How did you find out about this program? Are you participating in other programs or receiving services from another program?(probe for importance of telephone/stay at home program)

