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# Replication Manual Lifespan's Caregiver Respite Program



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# Replication Manual

## Lifespan's Caregiver Respite Program

### **INTENDED AUDIENCE**

The intended audience for this replication manual may be governmental or nonprofit aging service providers seeking to fill a gap in services for family caregivers of older adults who provide 80% of all long-term care support in New York State. This manual is provided at no-cost thanks to the support of the Helen L. Morris Foundation. Fee-based consultation is available from Lifespan.

### **INTRODUCTION**

Lifespan of Greater Rochester's Caregiver Respite program began in 2013 with a grant from the Helen. L. Morris Foundation through Rochester Area Community Foundation. The project focused on implementing and operating a caregiver respite service for families taking care of loved ones with early dementia or mild cognitive impairment. It was designed for easy accessibility to respite care with straightforward eligibility criteria.

Respite was provided as a collaborative effort between Lifespan and Community Place of Rochester utilizing trained, non-stipended Lifespan volunteers and stipended Senior Companions from Community Place.

Volunteers were trained using best practice standards to ensure the safety of care recipients and promote confidence in and ease of use for caregivers. The service was independently evaluated annually with an eye toward replicability and scalability to serve the needs of not only older adults with dementia, but also frail older adults and people with disabilities.

### **OUR CAREGIVER RESPITE PROGRAM FIVE-YEAR RESULTS**

Over a five-year period, 244 potential volunteers were recruited. One hundred and seventy volunteers provided respite. Three hundred and thirty-six caregivers requested respite and 76% were matched with a volunteer. One-third of the volunteers stayed with the program four to five years. Eighty percent stayed more than one year. (See Anita Baker Evaluation Report after the Appendices.)

### **A GUIDE TO REPLICATION — CREATING A SUCCESSFUL RESPITE PROGRAM**

**Goals for a caregiver respite service usually include some or all of the following:**

- Increase community awareness of respite services.
- Increase the number of volunteers providing respite services.
- Increase the number of people receiving respite care.
- Decrease caregiver stress.

Consider creating an advisory committee of stakeholders to assist with a needs/gap assessment, service planning and implementation.

**The advisory committee should:**

- Determine a vision — all stakeholders should share their vision for the project.

- Explore feasibility including whether other attempts to provide respite have been tried and review the successes and challenges of those programs.
- Identify demographic need.
- Assess needs and strengths of the community.
- Assess the availability of volunteers.
- Assess organizational readiness/capacity.
- Explore funding.
- Discuss service criteria and scope.

**Following the needs/gap assessment, consider the following for implementation:**

- Use of existing staff or capacity to hire new staff.
- Expertise in providing respite.
- Expertise in working with caregivers and assessing needs.
- Expertise in recruiting, training and supporting volunteers.
- Space for program staff and depending on the respite model, space to provide respite.
- Availability of, or ability to create a database to track volunteers, families and matches.
- Expertise in keeping accurate records and reporting to funders and stakeholders.

Determine your service inclusion criteria/target population. Demand for respite services in most communities will be far greater than the ability of any one agency or program to fill the need. This is especially true at the outset as volunteers are being recruited and trained. Inclusion or exclusion criteria helps target the correct populations and may include geographic boundaries, level of cognitive impairment, diagnoses, age, continence, behavioral issues etc. (Lifespan Appendix 1 - Caregiver/Care Receiver Assessment)

**Considerations**

Consider if a diagnosis requires verification from a medical professional or relies on information from caregivers.

Collaboration with other providers of caregiver services may allow access to an existing base of clients who could benefit from respite. Communications to caregivers should consist of messages to educate them about respite since it is not a commonly known term. It is also important to talk with representatives of different populations and identify leaders in those communities. It is vital that outreach materials and efforts for both clients and volunteers are culturally appropriate.

The Retired & Senior Volunteer Program or other agencies that recruit and train volunteers can provide access to expertise in recruiting, training and managing volunteers. Word-of-mouth can be the most effective way to recruit volunteers with paid and free media used to increase awareness of the opportunity to serve.

Ideally, the managing organization has a marketing/communication person or access to reduced cost advertising/marketing agency.

**ADOPTION — CHOOSING A MODEL**

**Single Organization or Collaborative**

One of the first choices in launching a respite service is whether a single agency manages and provides service or if the model will be a partnership. Management and provision of services by a single agency simplifies some processes.

The downside is that one agency needs to have the capacity to carry out all aspects of the program. If two or more agencies partner, it is vital to determine roles. One agency may take on more of an administrative role while the other agency provides services or both may do a mix of all tasks. Partnerships require decision-making and communication strategies.

### **In-Home or Congregate Respite**

Respite can be provided in a variety of locations and in a variety of ways. Depending on the demographics of the community and the availability of volunteers, respite can be provided in care receivers' homes or in congregate locations.

In-home respite allows caregivers to use the entire respite time for various activities. It can be easier for caregivers as there is not a need to travel to a site, and the care receiver is able to stay in familiar surroundings with little disruption to routine. In areas where geography or population density make in-home respite a challenge, communal respite models can be more effective and efficient. Some respite models include transportation to congregate respite locations. Other programs may include respite for caregivers who want to attend classes or events. Caregivers appreciate the provision of respite during caregiver support groups and education. While this is an important service, keep in mind that most caregivers use respite time to take care of personal needs.

The availability and frequency of respite is determined by the availability of volunteers. It can be offered multiple times a week, once a month or as needed. It may be provided by paid staff, volunteers or a combination of both. Most caregivers desire frequent, consistent respite. Communities who use a congregate, drop-off site model may choose to rotate the location with different faith communities or other organizations taking responsibility.

### **Donation/Fee or Sliding Scale**

Respite programs may be operated at no cost to the caregiver, on a sliding fee scale or on a donation basis.

### **Additional Caregiver Services**

Some respite models include consultation with caregivers regarding other services, educational opportunities, support groups, care management and opportunities for caregivers and or care receivers to socialize. Still other models make emergency respite, overnight respite, and/or respite for caregiver vacations or travel available.

When determining the scope of services, it is important to set parameters for both volunteers and caregivers. Tasks that are appropriate for volunteers are established. These parameters will be an important part of educating caregivers as to what they can expect from volunteers as well as educating volunteers about boundaries.

## **IMPLEMENTATION**

### **The following staffing roles were used in Monroe County.:**

- Program coordinator for oversight, reporting to stakeholders and funders, convening meetings, budgeting, evaluation and staff supervision. This person will also be involved in efforts to maintain and sustain the viability of the program.
- Accounting to handle invoicing and billing, budget oversight.
- IT to assist with technical needs including a data system for client and volunteer tracking.
- Marketing to assist with outreach and communication.
- Volunteer coordinator to recruit, vet, train, oversee volunteers and work with a care manager to make suitable matches between volunteer and caregiver/care receiver. The volunteer coordinator for a drop-in site would also schedule volunteers to assure adequate coverage for all hours of operation.

- Care manager/social worker to conduct home visits and assess the caregiver/care receiver's needs. In-home respite requires a home visit with both caregiver/care receiver. The care manager shares information with the volunteer coordinator. The care manager knows the family best and the volunteer coordinator is most familiar with individual volunteers. Care managers can provide on-going support and guidance for caregivers. As needs of the caregiver/care receiver change, the care manager will update staff so that services can be modified if appropriate or necessary.
- Most drop-in models have a site coordinator to oversee operation of the respite locations.  
(Lifespan Appendix #2 Job Descriptions)

## **VOLUNTEER RECRUITMENT**

Recruitment is an ongoing task for any respite provider relying on volunteers. Use all outreach methods, however word-of-mouth is often the best way to attract potential volunteers. Social media platforms provide a cost-effective tool. We regularly used Facebook to reach our 6,400 "friends," and sent email blasts to 11,000 current agency subscribers. We included articles about respite in the agency newsletter, and we printed and distributed rack cards and flyers. Publicity in a variety of formats placed at numerous venues and utilized in various types of media is important. Other venues include outreach to other service providers, appearances on local news programs, and speaking engagements at older adult centers, faith communities, retiree groups, veteran's groups, and service organizations. The personal ask was the most successful recruitment tool.

## **VETTING VOLUNTEERS**

Caregivers and care receivers need to trust that volunteers are thoroughly vetted, trained and oriented. These recommendations pertain whether a program is providing in-home respite or respite at a congregate location.

### **All volunteers must:**

- Have a criminal background check, sex offender status check and DMV screen or other procedures required by the agency.
- Be screened by the volunteer coordinator.
- Attend orientation and training.

### **Screening forms should be completed prior to orientation. These forms will likely include some or all of the following:**

- Application
- Consent for release of information
- Confidentiality agreement
- Interest inventory
- References
- Proof of valid car insurance and driver's license may also be required.

(Lifespan Appendix #3 Volunteer Application, Volunteer Agreement, Volunteer Interest Survey)

## **VOLUNTEER TRAINING AND SUPPORT**

A volunteer orientation and training manual is essential as it ensures consistent training. If volunteers will provide respite for someone with cognitive impairment, providing dementia training is imperative. Scripted training assures that every volunteer has been trained in the same way and given the same information. (Lifespan Appendix #4 Volunteer Policy & Training Manual) National organizations such as Faith-in-Action and ARCH have training materials available for use. The Alzheimer's Association's training is available online or through local chapters.

Contact volunteers regularly to support them, ensure the match is appropriate, and to learn if there are any challenges. Regular volunteer meetings are appropriate. Meetings are a time to share stories/resources and benefit from brief educational presentations. Volunteers can also be surveyed/interviewed at regular intervals or when changes occur to determine how satisfied they are with the program and the impact that it has on their life. (Lifespan Appendix #5 Volunteer Feedback Survey)

Policies and procedures for volunteers should be thoroughly reviewed at training. These can be shared with caregivers as appropriate. Caregivers and volunteers also will need information about insurance issues.

Training should include educating volunteers about caregivers' needs and how meaningful respite is to care receivers. Regular feedback from caregivers, care receivers and staff should be provided to volunteers. Sharing comments from caregivers/care receivers is a good way to let volunteers know how much they are appreciated.

Recognition for volunteers can include social gatherings, gift cards, birthday and holiday cards, certificates, notes and phone calls to stay in touch.

## **CAREGIVER/CARE RECEIVER INTAKE & ASSESSMENT**

The staff person (care manager/social worker) making the home visit should be experienced or be mentored by someone who is experienced in doing home visits.

### **Goals of the home visit includes:**

- Assessing the safety of the home including the presence of pets, location of firearms, number of people in the household, and relationships.
- Establishing if the care receiver is continent and ambulating independently, wanders or has aggressive behaviors.
- Determining if there are deficits in hearing or vision for the caregiver or care receiver.
- Verifying that the care receiver is living in the home or independent living unless the program provides services within assisted living facilities.

### **A home visit also evaluates:**

- Neatness of the home — difficulty with household chores, hoarding.
- Availability of edible food.
- Odors that might indicate the presence of pets or incontinence.
- Unsafe conditions.
- Accessible toilet facilities and ability to bathe.
- Untouched or neglected mail.
- Needs like grab bars or other accessibility equipment.

In addition to the items above, the staff member may request a brief tour of the home. It is a chance to identify family members (photos that are displayed) and hobbies or interests that may not have been mentioned. Asking the care receiver to do this is a way to assess how well they ambulate. If the family is reluctant it is important not to push the issue.

Staff should be trained to ask questions that determine caregiver and care receiver needs, wants and interests. Information about the home environment for in-home respite helps volunteers feel more comfortable. Volunteers should be given an opportunity to share their interests and parameters during orientation and training. Staff uses this information to make a good match.

At the home visit, the caregiver/care receiver may be asked to sign a release of information form so that staff can be in touch with primary care providers and other involved agencies as needed. Also at the home visit, caregivers are given a folder with privacy policies, staff contacts, additional caregiver services, and basic dementia information.

Following the assessment, a comprehensive, written narrative should be prepared. It needs to be detailed enough that a volunteer could enter the home or interact with a care receiver at a community-based program and not be surprised by anything. The narrative will be used by other staff who have not been present at the assessment. The narrative informs the team about who would be an appropriate volunteer for the family or what drop-in site would best meet their needs.

It is helpful to call the day before or day of the home visit to remind the caregiver and to make sure the visit is still convenient.

As much as possible the assessment process and follow-up should be with the same staff person. (Lifespan Appendix #6 Client Agreement)

## **CARE RECEIVER INTEREST SURVEY**

During the home assessment, the care receiver should complete (with assistance if needed) an interest survey. This is an opportunity to assess the care receiver's communication skills and memory. It also helps indicate how the person will interact with the volunteer. Staff should encourage the caregiver to let the care receiver use their own words. (Lifespan Appendix #7 Care Receiver Interest Survey)

## **THE MATCH!**

Following the home assessment, the care manager and volunteer coordinator attempt to match a volunteer with the family. Considerations include geographic proximity, interests/hobbies and availability. Caregivers, care receivers and volunteers may also request being matched with someone of a certain gender or cultural background. (We had one family who requested an Indian volunteer because they wanted someone who would understand cultural behaviors, food choices, etc..)

Once a volunteer is identified, information is shared. When the volunteer agrees, a staff person will contact the family to give them information about the volunteer, and if agreeable the volunteer calls the family immediately to schedule a visit. The care manager or other staff may offer to accompany the volunteer on the first visit.

Volunteers need to be oriented to caregiver/care receiver wants and needs. Staff must stay in communication with the caregiver and other identified family members so that everyone experiences peace-of-mind regarding the process. Regular, consistent visits from the volunteer helps build trust which is essential to success.

Caregivers need respite volunteers and agency staff to affirm their roles and recognize the isolation of caregiving. They need positive face-to-face interactions with agency staff and volunteers. It is important to note that caregivers need peace of mind. Developing trust with the agency and the respite volunteer is vital. To meet these needs, printed information can be shared with the caregiver regarding the role of caregiving and the impact on caregiver/care receiver.

Once the first visit takes place, the volunteer coordinator should follow up with the volunteer to see how the visit went and the case manager should follow up with the caregiver. If the visit did not go well, the reasons should be discussed with both parties and an offer made to look for a different volunteer. That holds true for the whole time a volunteer is assigned to a family.

Caregivers should be contacted on a regular basis by program staff to ensure that the volunteer is making visits and the match is appropriate. These calls are also a time to assess whether the caregiver needs additional services or information, if the status of the caregiver or care receiver has changed or to remind caregivers to use the time for themselves.

With respite in place, caregivers have the time and opportunity to focus on their health and well-being. Offering information about and access to a variety of evidence-based and evidence-informed programs such as Powerful Tools for Caregivers, Chronic Disease Self-Management, A Matter of Balance, Tai Chi, and PEARLS (Program to Encourage Active, Rewarding Lives) can enhance the ability of caregivers to care for themselves. Volunteers can serve as a sounding-board for caregiver concerns. [NOTE: Powerful Tools for Caregivers is a nationally available, six-week, evidence-based program developed by Stanford University and now managed by a non-profit in Oregon. Caregivers meet for 1.5 or 2.5 hours each week with other caregivers and are introduced to tools that encourage self-care activities.]

<https://www.powerfultoolsforcaregivers.org>

<https://www.ncoa.org/healthy-aging/chronic-disease/chronic-disease-self-management-programs>

<https://www.ncoa.org/resources/program-summary-a-matter-of-balance>

<https://depts.washington.edu/hprc/evidence-based-programs/pearls-program>

## **VOLUNTEER ACTIVITIES/ROLES**

Activities during respite range from sitting quietly to leaving the home to attend an event or go out to eat. At times, the volunteer may provide direct support activities to the caregiver such as light meal preparation, light housekeeping or laundry. If volunteers have trouble finding activities, they are encouraged to discuss the challenge with staff or other volunteers. (Lifespan Appendix #4 Volunteer Policies & Training Manual)

## **EFFECTIVENESS/EVALUATION**

A plan for regular evaluation of the program is essential. Whether an agency plans to do their own evaluation or hire an outside evaluator, it is important to anticipate the information needed for the evaluation process. Tracking data monthly helps identify trends and documents usage of the service.

The most obvious types of information will affirm all the ways in which the program impacts the well-being of caregivers, care receivers and volunteers. Outcomes and outputs are part of the planning process. Ensure they are being collected and tracked.

### **Useful evaluation tools include:**

- Annual evaluation surveys of caregivers and volunteers.
- Phone calls from staff to caregivers and volunteers to assess the match.

- Comments from volunteers on timesheets.
- Regular meetings with volunteers.
- Follow-up with families and volunteers when a case closes and for a period of time after that.

Volunteers and caregivers should be encouraged to comment about challenges or ideas they may have to improve service. Interviews with caregivers on an annual or semi-annual basis or at times of transition can determine how helpful the program is in relieving stress and giving caregivers time to take care of their own needs. (Lifespan Appendix #8 Caregiver Evaluation Survey). (Lifespan Appendix #9 Caregiver Respite Program Final Evaluation Report).

Regular meetings with the advisory committee and program partners also provide information for program improvement.

## **MAINTENANCE**

The program will need a method to maintain an “in-queue” list of those families not yet ready for respite. These are caregivers who call for information and then want to wait before scheduling an assessment. Depending on program policies, families may be removed from the list after a period of time.

It is necessary to have options available for caregivers waiting for a volunteer match. During the delay between assessment and assignment of a volunteer, staff should stay in contact with caregivers and offer alternative services to bridge the gap. Information about other resources and self-care tools can be given to them at assessment.

Sustainability also involves retaining volunteers. The investment in recruiting, vetting and training volunteers is substantial. Once a volunteer is ready to be matched, the quality of the match will impact how vested the volunteer will be and how long they will continue to volunteer. Careful attention must be paid to the needs of the caregiver/care receiver and volunteer. On-going support of volunteers is vital to sustaining the program. They need to believe they are making a difference, and that their role is valued and supported.

## **BUDGETING**

Budget includes salaries/fringe, the cost of space, heat, light, power, phone, background checks, marketing/communications/printing, recognition, mail, meetings, etc. Some programs may choose to provide a travel reimbursement for volunteers.

## **CASE CLOSING**

Cases close for a variety of reasons. The most common is a change in status of the care receiver such as the progression of dementia or other illness. There are times when a case closes because the family does not cooperate. Some caregivers set standards for volunteers that are challenging to meet — the time they will visit or what they are willing to do in the way of activities. Others find that having a volunteer in the home does not provide the relief they anticipated or complicates their life.

Support during times of change is vital to all involved. When a care receiver moves to a facility or their care needs go beyond volunteer level, it can be a time of loss for the volunteer, the caregiver and the care receiver. Staff need to stay in communication with the caregiver and volunteer to help them transition. Many volunteers continue to visit with the care receiver even when they are receiving care in a skilled nursing facility. The ties that are created are not quickly or easily forgotten.

Over time, programs will face the death of care receivers, caregivers and volunteers. It is important to recognize these as genuine losses for all involved. Volunteers grow close to families. They may need to be encouraged to attend services and allow themselves to grieve. Staff should send condolences to the family and the volunteer. Volunteers often choose to stay in touch or even visit with the family for a period of time after the case is closed. Volunteers may ask for a break before being re-assigned to a new family. Staff need to continue to be in touch and determine when the volunteer feels ready to take on a new assignment.

## **VOLUNTEER “RETIREMENT”**

Volunteers may need to stop volunteering or take a break at some point. If the case is still open, another volunteer will need to be assigned to the family as quickly as possible. The family should be informed of any changes. Having a list of volunteers who are willing to step in temporarily can alleviate issues with volunteers who travel in the winter or need to take leave for medical issues. They are also valuable in providing a short-term match until a permanent volunteer can be found. The caution with this use of volunteers is the impact on the family. Some families would prefer to wait rather than adjusting more than once to a new volunteer.

## **PLANNING FOR GROWTH**

As the program grows, challenges will arise. The number of volunteers almost never matches the need for respite. Policies may be needed to help decide who and how to help through respite.

## **LESSONS LEARNED**

A collaborative model with a lead agency has pros and cons.

### **Pros:**

- Expertise and experience of staff at both agencies.
- Existence of the Senior Companion program at Community Place and Faith in Action/Partners in Caring program at partnering agencies provided a solid foundation for this community’s program.
- Exposure/publicity provided by outreach staff at both agencies.
- Ability to utilize existing policies, procedures, training materials.
- Extended reach for diverse populations — ethnicity, language, culture, gender.
- Ability to learn from the experiences of both programs
- Ability to extend the reach of the Senior Companion program by funding the stipend and transportation for companions.

### **Cons:**

- Necessity of extensive and timely communication to ensure that things went as planned at both agencies.
- More people had input that needed to be considered.
- Work cultures had to be melded.
- Policies and procedures at both agencies needed to be reviewed and incorporated in the program policies and procedures.
- Agency forms also needed to be modified or combined for the program.
- High staff turnover rate at partnering agency.

## **Challenges with Caregivers/Care Receivers**

- Meeting specific requests for respite such as day of the week, time of the day, gender of volunteer.
- Caregivers who limit the choice of activities they want volunteers to provide.
- Caregivers who make demands that are beyond what can be expected of volunteers.
- Caregivers who waffle. They want respite but delay the matching process.
- Caregivers who are in denial about needing more assistance, or that their loved one needs a higher level of care.
- Ambivalence about needing outside help; not being able to provide care on their own; fear of interference or judging by an outside entity can complicate or delay the decision to seek respite.
- Some care receivers are not comfortable with strangers in the home or think they don't need a "babysitter."
- Some care receivers may be embarrassed at their need for a companion.
- Some care receivers are limited in their ability to carry on a conversation or engage with the volunteer.
- Care receivers may begin to exhibit behaviors that make it uncomfortable or unsafe for volunteer visits.

## **Challenges with Volunteers**

- Training is essential. It is an opportunity for staff to get to know the volunteer and decide whether or not the person will be an appropriate volunteer. It also helps the volunteer decide if the program is for them.
- Potential volunteers need to be as specific as possible about their interests, hobbies, and work experiences.
- Matching is complex and can be time-consuming. A good match is the magic of the program!
- Despite limitations volunteers make regarding their availability to volunteer and distance they are willing to drive, think outside the box and ask anyway. Use Google maps or a similar app to check distance.
- A consistent percentage of volunteers who proceed through vetting, training and placement decide that the role is not for them — which can be discouraging for staff.
- Timesheets can be challenging. Senior Companions do not receive their stipend or transportation reimbursement without a timesheet. For other volunteers, it often requires reminders via phone call or email/text. Many volunteers "just want to volunteer." They are not as compliant about reporting hours. Staff stress to them that the funder is expecting accurate data about the hours provided and that it is important for the future of the program.
- Volunteers need regular follow-up; they need a sense of purpose; and they deserve recognition.

## **DOCUMENTATION, DATA COLLECTION AND REPORTING**

Finding a software system that allowed us to track the type of data we needed was challenging. Volunteer tracking software often did not allow a three-way match (information about the caregiver, the care receiver and the volunteer). We developed an Access database.

## **CONCLUSION**

Respite is an effective way to reduce caregiver stress and improve efforts that help keep people at home as long as possible. One caregiver wrote, "Mom has thrived with the attention she is getting from her volunteer, and it's nice to get a break and feel that she is safe." The respite role also provides a fulfilling, flexible volunteer opportunity for older adults. As one of our volunteers said, "Helping others makes me feel good about myself. It's very rewarding!"

Lifespan Appendix # 1  
**Caregiver/Care Receiver Assessment Form**

**LIFESPAN-CAREGIVER RESPITE PROGRAM-CARE RECIPIENT ASSESSMENT**

**Date of Interview:** \_\_\_\_\_ **Date of Referral** \_\_\_\_\_

Name of Primary Caregiver: \_\_\_\_\_ DOB: \_\_\_\_\_ Age: \_\_\_\_\_

Address of Caregiver: \_\_\_\_\_ Relationship to Care Receiver: \_\_\_\_\_

How did you hear about this program? \_\_\_\_\_

Phone Number(s): \_\_\_\_\_

Primary Language \_\_\_\_\_ Race: \_\_\_\_\_

Email address of caregiver: \_\_\_\_\_

Additional/secondary Caregiver information: \_\_\_\_\_

\_\_\_\_\_

Name of Care Receiver: \_\_\_\_\_ DOB: \_\_\_\_\_ Age: \_\_\_\_\_

Address of Care Receiver: \_\_\_\_\_ Phone Number \_\_\_\_\_

Primary Language: \_\_\_\_\_

**Living Arrangements:**  Alone  with spouse/family member  Independent living  
 Other \_\_\_\_\_

**Pets in the home:**  Yes  No If yes, what kind/friendly? \_\_\_\_\_

**Services Requested** (Check all that apply)

<input type="checkbox"/>	Transportation to Appointments	<input type="checkbox"/>	Errands
<input type="checkbox"/>	Shopping with or for a person	<input type="checkbox"/>	Caring companionship
<input type="checkbox"/>	Medical escort	<input type="checkbox"/>	Stated needs
<input type="checkbox"/>	Occasional meal preparation	<input type="checkbox"/>	Laundry
<input type="checkbox"/>	Light housekeeping	<input type="checkbox"/>	Other (please specify):

**Time of day/day(s) of the week requested:**

**Needs Assessment:**

**Mobility:**

Walking:  Totally Independent  Needs Assistance  Unable

Do you use a:  Cane  Walker  Wheelchair  Bed bound  N/A

Have you fallen in the past year?  No  Yes \_\_\_\_\_

**Sensory Problems:** vision, hearing, swallowing, chewing \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

**Assistive Devices:** \_\_\_\_\_ Eye Glasses \_\_\_\_\_ Dentures \_\_\_\_\_ Hearing Aids \_\_\_\_\_  
 Oxygen \_\_\_\_\_ Insulin \_\_\_\_\_ PERS \_\_\_\_\_ Chair Lift \_\_\_\_\_ Grab \_\_\_\_\_ Bars \_\_\_\_\_  
 Commode \_\_\_\_\_ Ramp \_\_\_\_\_

**Medical Information:**

Primary Care Physician:

Name: \_\_\_\_\_ Phone number: \_\_\_\_\_

Address: \_\_\_\_\_  
 \_\_\_\_\_

Current Medical Issues/possible concerns: \_\_\_\_\_  
 \_\_\_\_\_ Smoker? \_\_\_\_\_

What other support is client receiving? \_\_\_\_\_ Relatives \_\_\_\_\_ friends \_\_\_\_\_ neighbors  
 \_\_\_\_\_ Church/synagogue \_\_\_\_\_ Meals on Wheels \_\_\_\_\_ Nursing Service \_\_\_\_\_  
 Social Worker \_\_\_\_\_ Day Program \_\_\_\_\_

Other community agencies: please specify \_\_\_\_\_

What type of assistance/support do the above give? \_\_\_\_\_

Is there an additional person/contact/neighbor to check on care receiver in an emergency?

Name: \_\_\_\_\_ Phone: \_\_\_\_\_

Address: \_\_\_\_\_

Do you prefer a male or female volunteer? \_\_\_\_\_ Male \_\_\_\_\_ Female \_\_\_\_\_ either one is fine.

**Do you feel your home is safe:** \_\_\_\_\_ Yes \_\_\_\_\_ No

Safety Risk Factor	✓ if Positive	Safety Risk Factor	✓ if Positive
Accumulated Garbage		No handrails on stairways	
Dirty Living Area		No light switch in reach of bedroom	
Traffic Lanes Obstacles		Loose rugs	
Cluttered Stairs/walkways		No grab bars in bathroom	
Doorways width inadequate		No rubber mat/decals in bathtub/shower	
Exposed Wiring		No access to phone/emergency #'s	
Inadequate Plumbing/Heating/AC		Smoking	
No Locks on Doors/Windows		No smoke detectors present	

Stairs not well lit		No carbon monoxide detectors present	
Stairs in poor condition		Insects/vermin	

**Caregiver's plans during respite time: (I.e. attending self-care medical/dental appointments)**

**Interview's name** \_\_\_\_\_

Please indicate your race/ethnicity (mark all that apply):

<b>American Indian or Alaska Native</b>	<b>Asian or Asian-American</b>	<b>Black or African American</b>	<b>Hispanic or Latino</b>	<b>Native Hawaiian or other Pacific Islander</b>	<b>White</b>		<b>Other</b>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>



## *Lifespan Appendix 2*

### **Job Descriptions**

#### **Program Director**

##### **SUMMARY**

Manages all aspects of education department and caregiver services including monitoring budgets and contracts, developing and monitoring outcomes for consumers and creating and implementing the long-range plan for the program. The program director is responsible for the fiscal and programmatic goals of the program.

##### **DUTIES AND REPONSIBILITIES**

- Develops and monitors program goals and objective within the policies and procedures.
- Develops and tracks outcome data.
- Tracks customer satisfaction of our services.
- Compiles internal quarterly operational reports. Implements corrective action.
- Submits timely funder reports. Communicates and fosters working relationships with funders.
- Regularly contacts advisory board members to review consumer outcome and satisfaction information and assist with market research for the development of new products and services.
- Implements quality assurance review for continuous program improvement.
- Monitors fiscal results and takes corrective actions as required.
- Assists in the development of new funding sources.
- Works in a team setting to identify gaps in service, suggest new products.
- Provides leadership and support for staff.
- Participates with staff in the hiring and orientation activities of new employees.
- Participates in the coaching, training and monitoring of staff.
- Completes annual performance reviews for all assigned employees.

##### **QUALIFICATIONS**

**EDUCATION:** BS or BA in adult education, social work, gerontology, human resources or training and development.

**EXPERIENCE:** 2 years of experience working with older adults. Proven ability and experience in public speaking. Administrative experience necessary.

##### **PHYSICAL AND MENTAL REQUIREMENTS**

- \* Ability to stand at least one hour at a time.
- \* Half of work is performed at a desk or at a personal computer station.
- \* Verbal, written and telephone communication skills are required.
- \* Public speaking is required.
- \* Ability to work in multi-cultural situations.

## **Program Coordinator**

### **SUMMARY**

Provides coordination of caregiving and respite contracts.

### **DUTIES AND RESPONSIBILITIES**

- Develop presentation materials for caregivers.
- Deliver community presentations and professional trainings.
- Maintain materials in Caregiver Resource Center.
- Assist with volunteer respite orientation sessions.
- Counsel families regarding caregiving issues.
- Oversee Powerful Tools for Caregivers classes.
- Participate in volunteer training and the matching process.
- Outreach to community organizations to connect with caregivers, care receivers and volunteers.
- Participate in events for disease specific organizations such as the Alzheimer's Association and Parkinson's Disease Foundation.
- General office management
- Database management.
- Monthly reports to funders and the agency.
- Schedule Powerful Tools for Caregivers classes. Assign leaders for Powerful Tools classes
- Assist in on-going program evaluation process.

### **QUALIFICATIONS**

Education: Bachelor's degree in Social Work, Human Services or related field

Experience: A minimum of two years working with caregivers. Must have knowledge of caregiver issues and community resources. Experience facilitating and leading groups.

### **PHYSICAL AND MENTAL REQUIREMENTS**

- \* Current, valid NYS driver's license
- \* Basic computer skills: Word, Outlook with ability in Excel and Access preferred.
- \* Basic knowledge of principles of human services research
- \* Ability to perform work at a desk or at a personal computer station
- \* Some standing during group presentations and professional trainings.
- \* Excellent verbal, written and communication skills are required
- \* Interface with all levels of personnel and with staff from other organizations
- \* Ability to maintain composure under deadlines
- \* Ability to work in multi-cultural situations
- \* Available for occasional evening or weekend events

## **CASE MANAGER**

### **SUMMARY**

The Case Manager assesses safety and eligibility of care receivers/caregivers to receive non-medical companion care/respite. Case manager provides on-going case management to ensure respite recipients continue to receive appropriate services and that referrals for additional services are completed. Works with Caregiver Respite Team to assist with matching an appropriate volunteer.

### **DUTIES AND RESPONSIBILITIES**

- Interview and perform home assessments of care receivers and their caregivers for non-medical respite care.
- Conducts in-home safety assessment and processes referrals to services that address concerns identified.
- Counsels care receiver and family about the respite services to be provided.
- Maintains documentation of client referral, assessment.
- Assists volunteer coordinator and respite team members with volunteer orientation and training, including how to cope with emergencies.
- Assists Caregiver Respite team with matching the volunteer companion with the care receiver/caregiver.
- Assists respite team with on-going volunteer companion support.
- Refers care receiver/caregiver to other programs as needs are identified. Referrals documented in the record.
- As appropriate, trains to facilitate Powerful Tools for Caregivers classes.
- Provides supervisor with client records and reports as required.

### **QUALIFICATIONS**

**EDUCATION:** Bachelor's degree in social work, human services, health care or related field.

**EXPERIENCE:** Three to five years' experience working with older adults, people with dementia, caregivers and families.

### **PHYSICAL AND MENTAL REQUIREMENTS**

- \* Current, valid NYS driver's license
- \* Must be able to multi-task in a busy environment
- \* Strong interpersonal skills necessary
- \* Ability to travel to client homes for assessment purposes.
- \* Excellent verbal, written and telephone communication skills required.
- \* Computer skills.
- \* Ability to work in multi-cultural situations
- \* Effective problem-solving skills
- \* Excellent team member
- \* Available for occasional evening or weekend events

## **VOLUNTEER COORDINATOR**

### **SUMMARY**

Responsible for the recruitment, volunteer orientation, training and recognition of volunteers for the Caregiver Respite program. Maintains volunteer records and manages volunteer database. Works with the team to match volunteers with care receivers. Provides supervision and support for volunteers.

### **DUTIES AND RESPONSIBILITIES**

- Arrange and conduct community presentations for visibility of Caregiver Respite volunteer program.
- Recruitment of volunteers and care receivers.
- Conduct outreach to community groups, faith communities, and volunteer organizations.
- Maintain acceptable level of active volunteers for programs.
- Meet, screen and orient individual volunteer applicants. Conduct and schedule volunteer orientation and training.
- Provide ongoing support for volunteers, including counseling, periodic check-ins.
- Assist with matching volunteer to caregiver/care receiver as needed.
- Gather and maintain data and files regarding volunteers and care receivers, and program files.
- Utilize databases.
- With support, processes volunteer hours and mileage, including data entry.
- Provide reports as required.
- Coordinate volunteer recognition.
- Assist in preparation of newsletters and other outreach to volunteers.
- Assist in ongoing program and volunteer surveys.
- Maintain up to date professional knowledge of the geriatric field, with special focus on Alzheimer's disease and dementia.

**EDUCATION:** Bachelor's Degree in social science, communication or related field or equivalent combination of education and experience

**EXPERIENCE:** 2 years of experience with volunteers and older adults. Working knowledge of community resources required. Basic knowledge about the impact of caregiving on the family.

### **PHYSICAL AND MENTAL REQUIREMENTS**

- \* Must be able to multi-task in a busy environment with attention to detail.
- \* A portion of the work is performed at a desk or at a personal computer station.
- \* Strong interpersonal skills necessary.
- \* Excellent verbal, written and telephone communication skills required.
- \* Some standing during group presentations and professional trainings.
- \* Computer skills (MS Office). Access, Excel experience preferred.
- \* Ability to work in multi-cultural situations
- \* Ability to travel by car. Must have reliable transportation and valid driver's license.
- \* Ability to work independently.
- \* Available for occasional evening or weekend events.

## **PROGRAM ASSISTANT**

### **JOB DESCRIPTION**

#### **SUMMARY**

Assist staff with the daily activities of the program by providing administrative and clerical support. Maintain a continual knowledge of the program by attending in-services and appropriate workshops.

- Perform general office duties as assigned (i.e. reports, letters, copying)
- Provide backup phone coverage, relay messages to appropriate staff.
- Schedule, communicate and attend and record minutes for team meetings, advisory council, etc.
- Maintain filing and record keeping systems for program.
- Assist with the coordination and set up of volunteer/companion trainings, process ID badges, and other tasks as needed for trainings and meetings.
- Compile data and complete needed queries and reports.
- Maintain and update all computer data for caregivers, volunteers and Powerful Tools for Caregivers participants.
- Assist with planning volunteer recognition event and special events or meetings.  
When appropriate, trains to facilitate Powerful Tools for Caregivers classes.

#### **QUALIFICATIONS**

**EDUCATION:** A.A.S. or related degree or equivalent combination of education and experience.

**EXPERIENCE:** Experience or equivalent training in ACCESS, Word, Excel.

#### **PHYSICAL AND MENTAL REQUIREMENTS**

- \* Majority of work is performed at a desk or personal computer station.
- \* Ability to maintain composure under strict deadlines.
- \* Excellent verbal, listening, written and telephone skills necessary.
- \* Strong computer skills.
- \* Must be able to multi-task in a busy environment.
- \* Ability to work in multi-cultural situations.
- \* Available for occasional evening and weekend events.



*Lifespan Appendix #3*

**Volunteer Interest Survey**

Your Name: \_\_\_\_\_

Birthdate: \_\_\_\_\_ Birthplace: \_\_\_\_\_

Spouse and years married: \_\_\_\_\_

Schooling and past occupations: \_\_\_\_\_

Places you've lived: \_\_\_\_\_

Children and Grandchildren: \_\_\_\_\_

Influential Family Relatives/favorite person: \_\_\_\_\_

Favorite memories (holidays/vacations, family trips): \_\_\_\_\_

\_\_\_\_\_

Pets: \_\_\_\_\_

Personality Traits (outgoing, reserved, conversational, sedentary): \_\_\_\_\_

\_\_\_\_\_

Any special likes/dislikes (i.e. topics to avoid): \_\_\_\_\_

Other information to share that would be of help with matching a care receiver: \_\_\_\_\_

\_\_\_\_\_

ACTIVITIES: Please describe leisure interests.

Community activities/Entertainment (dining out, coffee/tea, shopping, religious/church involvement, library, public market, senior citizens, concerts/movies/museums, historical events/sightseeing, YMCA): \_\_\_\_\_

\_\_\_\_\_

Outdoor activities (walking/hiking, gardening, biking, bird watching): \_\_\_\_\_

\_\_\_\_\_

Volunteer work (Food Co-op/bank, Veteran agencies, schools, nursing homes): \_\_\_\_\_

---

Sports/Hobbies (football, hockey, basketball, baseball, soccer, race car, fishing, hunting, stamp collecting, model trains, automobiles): \_\_\_\_\_

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Arts/Crafts (sewing/embroidery/knitting/crocheting, woodworking, stamping, painting/drawing): \_\_\_\_\_

---

Music and Dance (List genre and type of activities i.e. plays instrument, sings/dance, concerts etc...): \_\_\_\_\_

---

Table games (Chess/checkers, cards, puzzles, bingo, video games): \_\_\_\_\_

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# Lifespan Volunteer Application

Date \_\_\_\_\_

Name \_\_\_\_\_

Address \_\_\_\_\_

City/State/Zip \_\_\_\_\_

Phone # \_\_\_\_\_ Cellular Phone# \_\_\_\_\_

E-mail address \_\_\_\_\_

Under 55 \_\_\_\_\_ Over 55 \_\_\_\_\_ (required for some program eligibility)

Do you have transportation? \_\_\_ Yes \_\_\_ No Are you Retired? \_\_\_ Yes \_\_\_ No

Are you presently employed? \_\_\_ Yes Part-time or Full time (circle one) \_\_\_ No

### Employment:

Company	Position/Skills/Duties	Years

### Volunteer Experience:

Agency	Position/Skills/Duties	Years

Special skills, interests, hobbies: \_\_\_\_\_  
\_\_\_\_\_

Foreign languages spoken – please list: \_\_\_\_\_

List accommodations that you require in order to successfully perform volunteer activities:

\_\_\_\_\_

Have you served in the military? \_\_\_ Yes \_\_\_ No Branch \_\_\_\_\_

Are there months you are unavailable ? \_\_\_ Yes \_\_\_ No

Which months: From \_\_\_\_\_ to \_\_\_\_\_

Why are you interested in volunteering? \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

Have you ever been convicted of a criminal offense other than a minor traffic violation? \_\_\_ Yes \_\_\_ No

If yes, please attach an explanation of charges, date of offence, and status of charges on a separate sheet to be included with this application.

\*Prior convictions may preclude a volunteer from placement with certain assignments. Lifespan may share your application with its partnered agencies to better coordinate volunteer assignments. Some volunteer assignments require background checks that will be conducted by the partnered agency in accordance to their policies and procedures.

How did you hear about volunteering at Lifespan? *Check one or more*

Lifespan Website  Brochure  Newspaper/print  Mailing  Social media, Facebook

Presentation  Where I volunteer  Media/public service announcement

Referred by Other Volunteer. If so, who \_\_\_\_\_

Other (please describe) \_\_\_\_\_

.....

I permit...  I do not permit... Lifespan to use my photograph for publication, illustration, display, broadcast, or other marketing purposes at the discretion of the program.

I permit...  I do not permit...Lifespan to add me to their mailing list for future opportunities, publications, etc.

**Certifications:**

By signing below, I acknowledge that I have read and understand the following statements:

- I understand information can be shared with other Lifespan programs for volunteer opportunities.
- I understand that I am not an employee of Lifespan or the volunteer station and agree to serve without compensation.
- I understand that in my capacity as a Lifespan volunteer I may come into contact with confidential information. I agree to protect this information to the best of my ability and not to disclose it during or after my service as a volunteer has ended.

Volunteer Signature \_\_\_\_\_ Date \_\_\_\_\_

Lifespan Staff Signature \_\_\_\_\_ Date \_\_\_\_\_



# Caregiver Respite Program Volunteer Agreement

This agreement is intended to formalize the relationship between the agency and the volunteers. The agreement should be clearly understood by both the agency and the volunteers and be used as a way to ensure a productive and rewarding volunteer experience.

## Caregiver Respite Program

We at Lifespan agree to accept the services of \_\_\_\_\_ (volunteer name) and we commit to the following:

- To provide sufficient information, training, and assistance for the volunteer to be able to meet the responsibilities of the position.
- Complete job descriptions of each potential task the volunteers may complete.
- To ensure reasonable supervisory aid to the volunteer and to provide feedback on their performance.
- To respect the skills, dignity, and individual needs of the volunteer, and to do our best to adjust to these individual requirements.
- To be receptive to any comments from the volunteer regarding ways in which we might mutually better accomplish our respective tasks.
- To treat the volunteer as an equal partner with agency staff, jointly responsible for accomplishment of the agency mission.

## Volunteer

I, \_\_\_\_\_, agree to serve as a volunteer and commit to the following:

- To perform my volunteer duties to the best of my ability.
- To adhere to Caregiver Respite program policies and procedures, including recordkeeping requirements and confidentiality of agency and client information.
- I have received a copy of the Volunteer Policy and Training Manual, which includes job description of volunteer tasks.
- To meet time and duty commitment, or to provide adequate notice so that alternate arrangements can be made.
- To act at all times as a member of the team responsible for accomplishing the mission of Lifespan.

## II. Agreed to

Volunteer: \_\_\_\_\_ Date: \_\_\_\_\_

Caregiver Respite Program Representative: \_\_\_\_\_ Date: \_\_\_\_\_







# Lifespan Volunteer Respite Program

Volunteer Policies  
and Training Manual

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# **Lifespan of Greater Rochester**

## **Lifespan's Vision**

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Lifespan celebrates aging well by encouraging dignity, choice and independence. We are a recognized leader and focal point for age-related needs by providing valued, quality services. When our community thinks of the second half of life, it thinks Lifespan.

## **Lifespan's Mission**

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Lifespan is the only comprehensive agency in the community whose sole mission is to help older adults take on both the challenges and opportunities of longer life. We achieve this by providing a continuum of direct services, advocacy, guidance, professional training and community education.

## **Lifespan's Organizational Values**

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- We respect older adults and treat them with dignity.
- We provide services in a culturally sensitive manner and strive for diversity among staff and boards.
- We collaborate: when doing so, it enables us to better serve our customers.
- We continuously seek out opportunities to increase/improve services for older adults and caregivers.

## **Lifespan's Customer Outcomes**

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- Our services improve the quality of life for persons in the second half of life by...
- Increasing financial security
- Reducing the risk of elder abuse
- Improving caregiving
- Maintaining and increasing independence
- Increasing fulfillment
- Increasing options and knowledge

## **2. Mission and Purpose**

The Volunteer Respite Program was established to provide respite services for caregivers and individuals with cognitive impairments or early dementia. It is further intended that quality of life will be preserved and enhanced for every person served by the respite program.

## **3. Volunteer Policies**

The work done by volunteers is the heart of our organization. Our goal is that it should provide both satisfaction and a sense of accomplishment for our volunteers.

Every individual who agrees to carry out the mission of the Volunteer Respite program in a volunteer capacity is covered by the policies, procedures and guidelines provided at the time of initial training. **It is the responsibility of the volunteer to become familiar with these policies and to follow them.**

Volunteerism is designed to provide opportunities for personal growth, satisfaction, development and recognition. The policies contained herein do not constitute a contract of any kind and are subject to change at the discretion of the Volunteer Respite program.

### **Non-Discrimination**

Lifespan does not discriminate against an otherwise qualified volunteer because of disability or based on age. Neither do we discriminate on grounds of sexual orientation, race, color, ethnicity, religious affiliation, gender, creed, national origin, or socioeconomic status.

The Volunteer Respite program respects the personal beliefs of both its volunteer caregivers and care receivers. The program does not permit proselytizing or the maligning of any person's faith or politics.

The program does encourage interaction, acceptance and understanding among faith communities and other service organizations. The practice or advocacy of racism by any volunteer is not permitted. The program does not discriminate against a qualified individual with a disability about volunteer application, placement, training or other terms of the volunteer agreement. Neither does the Volunteer Respite program discriminate against care receivers on the grounds of disability or health status.

### **Appointment**

To volunteer, you are required to complete relevant trainings and a volunteer application reflecting accurately your individual qualifications, interests and skills related to this volunteer opportunity. Every effort will be made to match each volunteer in a way that will be rewarding and valuable to the mission of the program. Volunteers retain the right to be reassigned at any time after discussing the situation with the Volunteer Coordinator. You also have the right to determine your availability, the number of hours you wish to volunteer and to decline a match.

### **Volunteer Records**

Lifespan respects your privacy and all volunteer records will be maintained in a confidential manner. Volunteers' names, addresses or other personal information will not be released to any outside

organization or group for any reason without the written permission of the volunteer, unless such is required by law.

The term *volunteer*, in the context of this program, means that an individual gives of his/her time and talent without financial compensation.

### **Transportation (OPTIONAL)**

Volunteers who choose to provide transportation services must have a vehicle in proper working condition that is duly licensed and insured. All volunteers who transport care receivers must be at least 18 years of age and have a valid NYS driver's license and are subject to a LENS (License Event Notification System) check. Verification of this must be provided to the Volunteer Coordinator prior to starting to volunteer. The driver and all passengers must utilize seat belts at all times. In vehicles equipped with front seat passenger side air bags, we encourage care receivers who are frail or small in stature to sit in the back seat to avoid unnecessary injury.

A volunteer may provide transportation for shopping, errands, or for personal and medical appointments, or visiting. Lifespan is able to provide reimbursement for mileage, if requested. However, the miles you drive may be tax deductible at a higher rate. Mileage should be reported on your timesheet along with your hours for the month.

Care receivers to be transported must be ambulatory and may use a cane, crutches, or walker for self-assistance only. Volunteers are neither trained nor permitted to lift, transfer or otherwise attempt to transport a non-ambulatory individual. If a care receiver's condition becomes non-ambulatory, the volunteer should discuss needs with the Volunteer Coordinator and other support referrals will be made.

### **Accidents**

Any accident must be reported to the Volunteer Coordinator as soon as possible.

### **Insurance**

Volunteer caregivers who provide transportation services are required to maintain their own automobile insurance, which meets state minimum standards. Verification of this must be provided to the Volunteer Coordinator at the time of initial orientation or prior to commencing volunteer services.

### **The Role of Children and Teenagers**

It is by the example of caregiving adults that children and teenagers learn the value of using one's gifts in the outreach of volunteer support services. There may be ways that youngsters can share volunteer caregiving experiences and develop a pattern of personal service.

Before allowing children to participate in a visit or task, the adult volunteer must have made at least one visit to the care receiver. The volunteer should ask whether a visit by children would be welcomed or appropriate. If the care receiver is not comfortable with having children visit, that is to be respected. The elderly or disabled may not have been in the company of young children for some time.

- Volunteers must be responsible for the behavior of children during visits.
- Care receivers may be immune suppressed and by no means should anyone, adults and children alike, with colds, GI upsets or communicable disease be in their presence.
- Adults need to prepare children for any visit by discussing special needs of the care receiver.
- The volunteer may want to supply an activity for the child to share with the care receiver.
- Some tasks are more suitable for children to accompany the volunteer than others. For example, when it is important for the volunteer to be able to give undivided attention to the care receiver, children may interfere with that.

**In general, talk with the Volunteer Coordinator prior to involving children in volunteer visits.**

### **Use of Alcohol, Tobacco and Other Drugs**

The use, abuse, or possession of illegally obtained drugs, the abuse of over-the-counter drugs or prescribed medications, or the consumption of alcoholic beverages while volunteering is strictly prohibited. The use of tobacco is not permitted while volunteering with the care receiver.

### **Serious Illness Policy**

Lifespan is committed to the task of maintaining a healthy and safe environment for employees, volunteers, and care receivers. It is expected that everyone involved in the program will share this commitment, and all are encouraged to keep their immunizations up-to-date. It is the responsibility of each person to report any injuries or unsafe conditions to the program staff.

The program recognizes that volunteers with illnesses including, but not limited to, cancer, heart disease, and HIV/AIDS, may desire to continue to engage in as many of their normal pursuits as their conditions allow, including volunteering. So long as the individual can perform essential volunteer functions and medical evidence indicates the volunteering does not pose a threat of harm to him/herself or others, the volunteer will be encouraged to continue to perform volunteer assignments. But please do not volunteer if you are not feeling well. If unsure, please contact the Volunteer Coordinator for further guidance.

### **Code of Conduct**

Lifespan is committed to providing an environment in which interpersonal relationships are characterized by respect, dignity, courtesy, and equitable treatment. It is program policy to provide all volunteers with a work setting free of all forms of discrimination, sexual harassment, or abuse in any form.

Therefore, the organization will not condone or tolerate the following:

- Financial solicitation (selling products, raffle tickets, etc.)
- Display of sexual advances or activity between and/or among staff, volunteers, caregivers or care receivers.
- Use of the program name, related activities, facilities or publications for public or private promotion.

- Infliction of sexually abusive behavior upon anyone affiliated with the organization, including inappropriate touching or other bodily contact, exhibitionism, voyeurism or exposure to pornographic materials.
- Infliction of physically abusive behavior or bodily injury upon anyone affiliated with the program
- Emotional mistreatment of staff, volunteers, caregivers or care receivers, including verbal abuse or attack.
- Proselytizing or maligning any individual, faith or community group.

Lifespan reserves the right to refuse or revoke the volunteer status of anyone if that person advocates, solicits, or otherwise attempts to promote any form of sexuality to create substantial risk. Such conduct is detrimental to the proper environment for aiding those in need.

Any volunteer who believes that he/she has been the subject of abusive conduct by another is required to report the incident to the Volunteer Coordinator. Further action will be determined at that time.

All reports of abusive conduct will be documented and investigated. Law then dictates subsequent action. All reports remain confidential to the extent permitted by law.

### **Resolution of Problems**

When problems or grievances arise in the performance of volunteering, the following steps are taken until the problem is resolved. All parties involved shall maintain strict confidentiality throughout the process:

- For minor concerns, the volunteer notifies program staff first and discusses the situation with the caregiver if appropriate.
- If this does not resolve the problem, or the volunteer or caregiver wishes to pursue the issue further, we will follow Lifespan's Grievance Policy. Every effort will be made by program staff to resolve the situation.

### **Release of a Volunteer**

Continued service by some volunteers may not always be in the best interest of the mission. Some significant problems may make it necessary to release a volunteer. This action to release a volunteer will receive careful, detailed and confidential consideration. Some reasons for release of a volunteer may include but are not limited to:

- Neglect of responsibilities.
- Financial abuse or taking payment for services.
- Physical, verbal, sexual, or emotional abuse of a care receiver, another volunteer, or staff member
- Use of illegal drugs or abuse of any substance while performing volunteer services.
- Racism or discrimination in any form.
- Arrest and/or conviction for a misdemeanor or felony other than a simple traffic violation.
- Disregard for the safety and well-being of a care receiver.
- Proselytizing or maligning any faith or community service group.
- Violation of confidentiality.

- The appearance of sudden serious alteration in a volunteer's mental, physical or emotional capacity that in the estimation of the program staff impacts the volunteer's ability to perform effectively.

A volunteer may be released without advance notification or the opportunity to appeal the organization's decision. These actions are rare and solely for the protection of the mission, purpose, and community responsibility of the program.

### **Episodic Volunteering**

While it is recognized that volunteers need flexibility, it is in the best interest of the Volunteer Respite program to engage volunteers who can make long-term commitment. It is recognized that volunteers need flexibility in their opportunities for service. When possible, such volunteers will be accepted for short-term assignments. They will participate in volunteer training and abide by all established policies and procedures. Volunteers seeking temporary or short-term work to satisfy course or community service requirements will be interviewed by the Volunteer Coordinator. It is likely that such support and assistance can be utilized. The program will attempt to utilize the gifts of all individuals whenever possible. There may be times when a volunteer cannot be placed because of his/her limitations or the unavailability of current suitable assignments. Those who travel for an extended period of time may remain on the volunteer roster and may resume active status once they return to the area.

### **Reporting Hours of Volunteer Service**

All volunteers are required to document and report service hours monthly. Forms will be provided by the Volunteer Coordinator and may be copied if convenient and necessary. Documentation of hours and miles driven (if requesting mileage reimbursement) must be submitted to the program office by the 5<sup>th</sup> of the following month.

### **Crisis Plan**

The general rule is "SAFETY FIRST" and remember that caring is what we do.

If your school district (or the school district of your care receiver) is closed for weather-related concerns, we encourage you to stay home as well. If any other circumstances raise doubt in your mind for travel, please simply call the Volunteer Coordinator to discuss options.

If no one comes to the door in response to a scheduled visit or transport, contact the caregiver first, then the emergency contact or the Volunteer Coordinator to communicate your concern and to see if caregiver/receiver's location may be known. You will be provided with those phone numbers when you are matched with a caregiver/care receiver.

In the event of a scheduled phone contact, if the caregiver/receiver does not answer, try again in 5-10 minutes and let the phone ring a while. Then call an emergency contact with your concern. If no explanation of the caregiver/receiver's whereabouts is obtained, call the Volunteer Coordinator for guidance.

**In the event of any occurrence or situation involving an actual or perceived threat to the life or well-being of a caregiver/receiver, volunteer or any person affiliated with the program, immediately**

**contact 911 for assistance. Give priority to the safety of the individual. Take such action as is necessary to reduce danger and/or obtain necessary assistance.**

Please notify the Volunteer Coordinator as soon as possible after resolving the situation.

### **Suspected Elder Abuse**

**If you suspect abuse or neglect of your care receiver, you are required to contact program staff.**

### **4. Confidentiality and Reporting**

One of the joys of volunteering is the relationship you will develop with your care receiver. Through this bond, however, you may come to know sensitive information, either by observation or from sharing by your care receiver.

Sensitive information and how it is to be handled can produce awkward and uncomfortable situations for you. Keep in mind several basic guidelines which can make this easier:

- Caregivers, care receivers and their wishes should be respected always.
- It is critical that all information learned in a visit be treated with confidentiality.
- At no time should information be shared with others — even mutual friends.

**If you are in doubt as to whether information should be treated as confidential, treat the information as confidential until you ask your caregiver/care receiver for permission to share it.**

Your observations, whether they relate to the physical condition of your care receiver, medication, diet or treatment compliance, or, second-hand information you have received from family or friends must be treated as confidential and should not be disclosed to anyone except the program staff. Should you feel you need to pass along information or observations to the care receiver's family or the care receiver's medical caregivers, and you have not had the opportunity to receive permission, you must refrain — unless a true medical emergency exists.

If you suspect that your care receiver's health may be deteriorating substantially, contact program staff immediately to discuss notification of the care receiver's family in a generalized way that respects the independence and right of your care receiver to make his or her own decisions.

### **5. Discussing Spiritual Issues**

#### **Do we talk about spiritual issues?**

Health care systems now are adopting a new definition of health to include physical, emotional, social, and spiritual well-being. When dealing with a client, spiritual issues may arise.

Many volunteers may find it difficult to answer some of the spiritual issues that people, especially people with pressing needs may pose. Clients may ask tough questions. These questions may make you feel uncomfortable or defensive. Keep in mind that people may

believe much differently than you do and that is OK. Caring, non-judgmental listening is often what is most helpful. If their beliefs present a problem in the caregiving relationship, you may ask to be assigned to assist another client. Please be sure to let program staff know if spiritual concerns arise.

## **6. General Guidelines for Service**

- The volunteer generally performs only assigned duties. If the volunteer wishes to do more or is asked to do more by the care receiver/family, the volunteer should discuss this with the Volunteer Coordinator first.
- The volunteer will make every effort to set up a mutually acceptable time for respite caregiving with the family. If you are unable to keep the agreed-upon time(s), you must notify the family ASAP and ideally reschedule for another time in the near future so as not to disappoint the family.
- The Lifespan Respite program suggests that a volunteer not give personal phone numbers to the care receiver to provide boundaries for the volunteer experience. This may be judged on a case-by-case basis.
- If the personal situation of a volunteer changes and they are unable to perform assignments, the volunteer must notify the Volunteer Coordinator as soon as possible.
- The volunteer is a guest in the caregiver/receiver's home.
- The volunteer will not ordinarily enter a home when no one answers. See Crisis Plan, emergency procedures.
- The volunteer is expected to be highly dependable and on-time.
- The volunteer needs to be an active listener, sharing personal experiences and special interest as appropriate, but returning focus on the caregiver/receiver.
- The volunteer should not offer legal, medical, financial or personal advice. Such issues need to be referred to the Volunteer Coordinator to arrange further assistance.
- The volunteer will not lend money or other items to the client.
- The volunteer will not accept payment for services provided. If the caregiver/receiver is insistent, suggest that they donate to Lifespan, and then provide the caregiver/receiver with a self-addressed envelope to return to the office. (Donation envelopes are available by contacting program staff.)
- The volunteer is encouraged to be creative in caregiving. As a relationship grows, one party may wish to include the other in a family meal, celebration or other activity. If concerns arise, consult the Volunteer Coordinator.
- When a volunteer discovers changes in a client's needs, mobility or health status, it is recommended that the Volunteer Coordinator be informed.

- A volunteer should always identify him/herself to the care receiver by showing the identification card provided by Lifespan.
- Volunteers are required to familiarize themselves with the guidelines for each task to be performed (see Volunteer Job Descriptions section of this manual).

## 7. Characteristics of Volunteer Caregiving

**Giving of yourself:** Volunteers are special friends for the caregiver/receiver and they will look forward to your visits. In the volunteer context, the caregiver/receiver comes first and should never feel like a burden.

**Meeting Expectations:** Establish a consistent schedule with the caregiver/receiver on which they can depend. Cancellations should be infrequent. When cancellations are necessary, call the caregiver/receiver as soon as possible.

**Problems are addressed as they arise:** When problems arise, concerns need to be discussed openly with the program staff.

**Boundaries and limits are set:** If the family asks you to do something outside of your role as a volunteer, it's OK to decline. For example, they could ask you to stay overnight or do heavy cleaning chores. These tasks are not part of our volunteer program. If asked, please decline and let program staff know, so the family can be linked to other support services to address their request.

**Support is offered freely and without judgment.** Listening is key. As a volunteer, you are there to listen, support, explore options, but not to give advice. We all have values that we bring with us as we go through life. Values may vary, for example: housekeeping standards.

**Confidentiality is maintained:** Unless there are situations that involve:

- Suspected or known abuse (financial, physical, sexual)
- Neglect (little food, unsafe living conditions, dirty clothing, offensive body odor, etc.)
- Imminent danger to self or to someone else (weapons, self-harm)

**If a volunteer has a concern as noted above, the Volunteer Coordinator should be called immediately. Call 911 if there is immediate danger**

## 8. Volunteer Skill Development

### Listening Skills

Listening is an art, a skill, a discipline, and like other skills, it needs self-control. You must understand what is involved in listening and develop the necessary techniques to be silent and listen. You must ignore your own needs and concentrate attention on the person speaking. Hearing becomes listening only when you pay attention to what is said and follow it very closely.

**Demonstrate that you are listening by:**

- Your body language
- Echoing words
- Making eye contact
- Nodding your head
- Keeping your body relaxed and open
- Leaning towards the speaker

**The purpose of good listening is to:**

- Show your support and help the other person relax.
- Show you are accepting them, and are open to them.
- Enable each one to speak and be heard.

**You can acknowledge, affirm, and encourage others to “let off steam” and explain their concerns by using verbal cues, such as:**

- “I see.”
- “I understand.”
- “That’s a good point.”
- “I can see that you feel strongly about that.”
- “I can understand how you could see it like that.”

**You appear relaxed and empathetic when you:**

- Ignore distractions.\
- Sit close (but not too close) and slightly forward.
- Make eye contact.
- Listen rather than talk.
- Reflect what the person is saying.
- Ask questions to clarify what you heard and to clear up misconceptions and check assumptions.
- Listen before being directive (if indeed you ever are directive.)
- Provide silence to encourage the person to talk.
- Avoid quick conclusions.
- Listen with your third ear... to:
  - Feelings, Thoughts, Attitudes, Opinions, Body language, Facts.

**Sample Self-Assessment for Listening** (Circle the appropriate column)

**Learning How to Listen**

Yes	No	Sometimes	Do I pay attention?
Yes	No	Sometimes	Do noises in the room interrupt my listening carefully?
Yes	No	Sometimes	Am I willing to judge the speaker's words without letting my own ideas get in the way?
Yes	No	Sometimes	Do I find the speaker's personal habits distracting (e.g., clearing the throat constantly?)

**Listening for information**

Yes	No	Sometimes	Can I mentally organize what I hear so that I can remember it?
Yes	No	Sometimes	Can I think up questions to ask the speaker about ideas that I don't understand?
Yes	No	Sometimes	Do I get the meaning of unknown words from the rest of what the speaker says?

**Listening Critically**

Yes	No	Sometimes	Can I separate facts from explanations or opinions?
Yes	No	Sometimes	Can I tell the difference between important and unimportant details?
Yes	No	Sometimes	Can I pick out unsupported points that a speaker makes?
Yes	No	Sometimes	Am I able to pick out specific words or phrases that impress me as I listen?

**Listening Creatively**

Yes	No	Sometimes	Am I able to put what I hear into my own words so that I can paraphrase back what I hear?
Yes	No	Sometimes	Do I become involved in the poem, story, essay, or play so that it appears the action is truly taking place?

## Communication Shutdowns

1. Don't be ridiculous.
2. That's not my responsibility.
3. We don't have time.
4. We've never done that before.
5. If it ain't broke, don't fix it.
6. We're not ready for that.
7. We tried that before and it didn't work.
8. It simply can't be done.
9. It's too radical of a change.
10. It's not really our problem.
11. Let's get back to reality.
12. We have done alright without it all this time.
13. It won't work here.
14. I don't personally agree, but if you insist.
15. Are you crazy?

## Seven Levels of Listening

- 1. Not listening:** Not paying attention to or ignoring the other person's communications.
- 2. Pretend listening:** Acting like or giving the impression that you are paying attention to another person's communications, but in actuality not really paying attention to that individual.
- 3. Partially listening:** Only focusing on part of the other person's communication or only giving it your divided attention (while texting on your phone or watching TV....)

**4. Focused listening:** Giving the other person your undivided attention to his or her communication.

**5. Interpretive listening:** Going beyond just paying attention but really trying to understand what the other person is communicating.

**6. Interactive listening:** Being involved in the communications by asking clarifying questions or acknowledging understanding of the communication.

**7. Engaged listening:** Being fully engaged in communications involves listening to the other person's views, feelings, interpretations, values, etc., concerning the communication and sharing yours as well with the other person(s). In engaged listening, both parties are given the opportunity to fully express their views, feelings, and ideas.

Which level(s) of listening do you think might work best while spending time with someone diagnosed with dementia?

Reproduced and edited from:

**50 Communications Activities, Icebreakers, and Exercises by Peter R. Garber, Amherst, MA, HRD Press, 2008.**

### **Developing Healthy Boundaries**

Signs of healthy Boundaries

- Appointment times are adhered to.
- You offer non-judgmental support.
- You are patient and gentle while speaking the truth.
- You are cautious about giving or accepting favors and adhere to program policies.
- You are able to say "no" if asked to do things outside of your job description / time availability.
- You do not take blame for things you are not responsible for.
- You cultivate positive regard toward and appropriate detachment from the client.
- You maintain a calm and pleasant demeanor.

### **Signs of Unhealthy Boundaries**

- Accepting food, gifts, touch that you don't want or are against policies.
- Touching a person without asking.
- Allowing someone to take as much of your time and energy as they can and then feeling overwhelmed by the person.
- Believing others can anticipate your needs and expecting others to fill your needs automatically.
- Falling apart so someone will take care of you – needing rescuing.
- Telling all, talking at an intimate level on the first meeting, falling in love with a new acquaintance or anyone who reaches out to you.
- Giving as much as you can for the sake of giving, or taking as much as you can for the sake of getting.

- Going against personal values or rights to please others.
- Letting others define you, describe your reality and /or direct your life.
- Not noticing when someone else displays inappropriate boundaries. Not noticing or caring when someone invades your boundaries.
- Self-abuse or abuse of others.

### Ways to Communicate Boundaries and Suggested Responses

- **Inform:** Educate people in advance. “I respect the policies of the agency and the policy states that volunteers are not allowed to do home repairs.”
- **State Identify Boundary** as soon as you realize it is being violated. “I’m sorry, but I am not allowed to do home repairs.”
- **Request:** Ask, then demand that the other person stop or comply. “Please, don’t keep asking me to fix the window.”
- **Instruct:** “I need you to not ask me to fix the window.”
- **Warn:** Extend the boundary – “In the future I expect you to find someone to do your home repairs so you do not ask me.”
- **Leave:** Walk away and explain why you are walking away – “I have to leave now; we are done with your shopping and I can’t do any home repairs. I will be violating agency policy.”

### Polite Ways of Saying No

**Straight Forward:** “No, I cannot stay.” Be careful of the temptation to explain. “NO” is an answer.

**Pleasantly:** “I’d much rather stay and chat, but unfortunately I have to leave.”

**Buying Time:** “This sounds like an important concern. Could we talk about it on Friday when I have more time?”

**Alternative solution:** “It sounds like you are having a hard time with this. I don’t feel qualified to help you. Have you spoken to your doctor about it?”

### Conversation Skills

Use open ended questions to encourage the person to talk more about the problem, such as:

- Can you tell me more about ....?
- Would you like to talk about ....?
- Can you tell me what that means to you?
- How would you like things to be?
- What do you imagine happening down the road?
- How do you see things changing?
- What would you like to do about....?
- I’m wondering ....?
- What’s most important for you know?

Use “I” messages to encourage resilience.

I felt (use a feeling word “upset”) when (describe the situation “the milk was spilled”) because (how it affects you “I had to clean it up”). If (describe change “it can be poured into a bigger cup”) then (logical consequence “it won’t get spilled again”).

### **Recognizing Signs of Caregiver Burnout**

As the Respite Volunteer, you may observe the signs noted below. You may provide active listening and support. However, you are not responsible for diagnosing or treating the caregiver’s burnout. Please notify the Volunteer Coordinator if you have concerns about the caregiver.

- Irritability
- Sleeplessness
- Depression
- Anxiety
- Exhaustion
- Headache, stomach-ache, or other physical health problems
- Alcohol or substance misuse
- Family problems
- Abuse of care receiver.

## **9. Volunteer Job Roles**

### **Friendly Visiting**

1. The volunteer should telephone the care receiver the day before the visit to confirm the time.
2. The volunteer can knock loudly or ring the doorbell upon arrival. Allow time for the elderly or disabled to respond.
3. Enter the home slowly and quietly with respect for the client’s privacy. Identify yourself with your Volunteer ID as necessary.
4. Do not smoke in the client’s home.
5. Avoid being loud or boisterous in conversation. Follow your client’s lead.
6. Be aware of signs that the care receiver wishes the visit to end.
7. When visiting a person who is confined to bed, stand or sit on a nearby chair to be seen and heard. Do not sit on the bedding.
8. The volunteer is to be pleasant, cheerful, patient, sincere and friendly, wearing a warm smile.
9. Avoid controversial topics even when initiated by the client. Heated discussion is not the purpose of a supportive and caring visit.
10. Avoid giving medical, legal, or relationship advice. Suggest that these matters be taken up with the professionals involved in the client’s life. Consult the Volunteer Coordinator if referrals seem to be indicated.

### **Light Housekeeping (OPTIONAL)**

1. The volunteer should phone the caregiver to arrange a day and time to help with household chores. During this call the extent of the work to be done should be discussed, so the volunteer can schedule adequate time for completion. The caregiver should be reminded to have all of the necessary cleaning and laundry supplies on hand.
2. The volunteer should establish with the caregiver a list of simple chores to be done.
3. The volunteer should inquire about specific brands of housekeeping products to be used. The caregiver is to provide necessary cleaning products and utensils. The volunteer is responsible for reading product directions and proper use of cleaning products. Caution is recommended if using products that require the area to be well ventilated. Keep in mind the sensitivity of the client to the fumes. The volunteer is responsible for his/her own safety and the safety of the client when using household cleaners. The volunteer is to avoid use of cleaners for applications not specified by the manufacturer.
4. The volunteer may wish to wear protective gloves to guard against disease and irritation.
5. The volunteer should be sensitive to the fact that everyone cleans in a different manner. If the client gives specific instructions for the way tasks are to be done, the volunteer should comply to the best of their ability.
6. The volunteer should be certain that trash is properly bagged and in the location for collection. If medical waste is involved, consult the Volunteer Coordinator.
7. The volunteer should use caution when handling possessions of the client.
8. If the volunteer is unable to finish the task in the time allotted, he/she should arrange a time to return for completion if agreed-to and practical.
9. The volunteer should do **only** light housework. A volunteer is not expected to do heavy cleaning such as moving furniture or washing walls.
10. Chores that require the use of a stool or stepladder are discouraged.

### **Shopping with a Care Receiver (OPTIONAL)**

Families are responsible for providing funds for shopping, cleaning supplies, repair materials or other expenses incurred for the benefit of the care receiver. Should a volunteer discover that the family is not in a financial position to provide funding for necessary items, the volunteer is to discuss the need with program staff.

- The volunteer should contact the family in advance to schedule the shopping trip.
- A shopping list is to be prepared by the family prior to the outing.

- The volunteer can establish how many stores will be shopped, which stores, and the approximate time to be spent.
- Before departing the family's home, check to see that the shopping list, cash, checks, credit cards, coupons, prescriptions, insurance cards, etc. are in hand.
- Discuss with the family what assistance is desired (accompanying the care receiver fully or returning at a specified time and place.)
- Assist in carrying packages as needed and handle purchases with care.
- The volunteer helps to carry purchases into the home and aids in unpacking, remembering to store items needing refrigeration properly.
- A shopping receipt (provided by Lifespan) must be completed and signed by the volunteer and the family. A blank receipt is included in your volunteer folder.
- The volunteer and family may arrange a future shopping trip before parting.

#### **Shopping for a Care Receiver – Errands (OPTIONAL)**

1. The volunteer should contact the family in advance to schedule the shopping trip and determine what stores are to be visited to complete the shopping task.
  - A shopping list is to be completed that includes specifics on items to be purchased (brand names, size of product.)
  - Ask if substitution is acceptable if the preferred brand or size is unavailable, excluding prescriptions.
  - Determine if the cost of the item is important or if the brand is most important. Ask if a less expensive brand can be substituted for the listed one.
  - Ask if coupons are to be used.
  - When possible purchase non-breakable containers; handle purchases with care.
2. For the protection of the volunteer, a receipt must be given to the family for the money exchanged for purchases. A blank receipt is included in the volunteer folder.
3. Upon return, give the family the cash register receipt, change, and complete the initial receipt by having the family member sign in agreement. One copy remains with the family and one is given to the Volunteer Coordinator.
4. Assist in unpacking, making certain that items requiring refrigeration are properly stored.
5. If indicated, explain why an item was not obtained.

6. The volunteer and family may arrange a date and time for the next shopping assistance.

### **Transportation (OPTIONAL)**

Non-emergency transportation is an optional part of our program. If a client is already receiving services and requests transportation to a doctor's appointment, the family should make every effort to find an existing volunteer transportation program. If a respite volunteer is willing to drive, here are the general rules for safe transportation:

1. Seatbelts must be worn always by the driver and passengers.
2. The volunteer is to call the family 1 – 2 days prior to the scheduled appointment to confirm arrangements.
3. The volunteer should allow extra time for unknown traffic, weather, parking or other transport factors.
4. The volunteer should ask the caregiver about any special needs or assistance that may be required. It is important to note that volunteers are not expected to lift a care receiver in or out of a vehicle.
5. When driving in inclement weather, use extra caution. Reschedule the outing if travel is hazardous.
6. The volunteer will try to park as close to the care receiver's door as possible and not occupy handicapped spaces without proper identification displayed on the car.
7. Be aware of physical limitations of the care receiver about stairs and distances by driving up close to buildings, encouraging the use of handrails and other assistive devices as needed.
8. If transporting to an appointment, the volunteer will estimate the time needed for the appointment and will clarify whether he/she will wait onsite or return at a specific time. If transportation is to a medical appointment, tell medical office staff of the plan as well.
9. Obey all traffic laws, regulations, and speed limits. Be a safe and courteous driver.
10. Volunteers are **NOT** permitted to operate the family's car. Contact program staff in special circumstances.
- 11. In the event of a fall, seek assistance from the doctor's office, or call 911. Do not attempt to lift or move the care receiver.** Remain with the care receiver until help arrives.

### **Medical Appointment Escorts (OPTIONAL)**

1. Write down care receiver's questions prior to the appointment.
2. Go into the visit with the care receiver if the care receiver/caregiver wishes.
3. Take notes of what is told to the care receiver in terms of medical follow up or medical condition by the medical staff.

4. Assist the care receiver to ask his/her questions of the medical staff and note responses.
5. If time permits and the volunteer is available, transport the care receiver to any necessary follow-up tasks, such as visiting the pharmacy.
6. Discuss the information received from medical staff with the care receiver and their caregiver after the appointment.



*Lifespan Appendix # 5*

## **Volunteer Feedback Survey**

Please take a few minutes to provide us with important feedback that will allow us to better serve caregivers and their loved ones. Your responses are confidential, and you may skip any question you do not wish to answer. *If you are no longer actively volunteering, please think about the persons you most recently worked with.*

**Please fill out one survey for each match you have had or are currently serving. You can obtain another survey by clicking on the link in your email. THANK YOU!**

Your Name \_\_\_\_\_

**How meaningful is this volunteer work to you? (check one)**

Not meaningful     Somewhat meaningful     Meaningful     Very meaningful

Please use the space to add any further comments.

**Why did you become a Caregiver Respite program volunteer?**

**How helpful was the Caregiver Respite training you received? (check one)**

Not helpful     Somewhat helpful     Helpful     Very helpful

**Do you need more training?**     NO     YES

Please use this space to describe any further training you need

**How would you rate the support you receive from Lifespan? (check one)**

Not helpful     Somewhat helpful     Helpful     Very helpful

Please use this space to clarify further if needed.

Please rate the overall usefulness of the Caregiver Respite Program to the Caregiver that you are serving (*check one*)

Not useful     Somewhat Useful     Useful     Very useful

Overall, how satisfied are you with your Caregiver Respite volunteer experience? (*check one*)

Very Dissatisfied     Dissatisfied     Satisfied     Very Satisfied     Prefer not to say

How likely are you to . . . (*mark one answer on each row*)

	Not Very Likely	Likely	Very Likely	Not applicable
a) continue volunteering for the Caregiver Respite program				
b) recommend Lifespan to others as a place to volunteer				

**YOUR FIRST/ MOST RECENT MATCH**

Last name of **care receiver** (please think of this person and his/her caregiver -- and caregiver companions—when you answer the rest of the questions in this section).

Did you do any of the following for this **CARE RECEIVER?** (*check one answer on each row*)

	Never	Occasionally	Frequently
Share a meal or prepare food for him/her			
Go on outings			
Watch TV with him/her			
Play cards or other games with him/ her			
Take him/her for a walk or other outing			
Provide transportation			
Friendly visiting/companionship			

Please use this space to describe any OTHER activities you do for this care receiver.

**Did you do any of the following for this person’s CAREGIVER? (check one answer on each row)**

	Never	Occasionally	Frequently
Light housekeeping			
Yard work/snow removal			
Minor home repair			
Run errands			
Provide listening/support			

Please use this space to describe any OTHER activities you do for this care receiver.

**In a typical week, about how many hours did you spend with this care receiver and caregiver?**

**How good a match would you say you are for... (mark one answer on each row)**

	Not a very good match	Okay	A good match
a) The care receiver			
b) The caregiver			

**How well prepared were you to take on this volunteer role? (check one)**

Not prepared     Somewhat prepared     Prepared     Very prepared

**Do you need more support from Lifespan with regard to this care receiver/caregiver?**

NO  YES

Please use this space to describe additional support you need.

**How helpful would you say your assistance is overall . . . ? (mark one answer on each row)**

	<b>Not at all Helpful</b>	<b>Somewhat Helpful</b>	<b>Very Helpful</b>
a) To the care receiver			
b) To the caregiver			

**Would you say that your visits have helped reduce the caregiver's stress? (check one)**

No  Somewhat  Yes

*Please clarify your answer to Question 18 in the space below if needed.*

**Would you say that your visits have helped improve quality of life for the care receiver? (check one)**

No  Somewhat  Yes

*Please clarify your answer to Question 15 in the space below if needed.*

**Which category below includes your age?**

18 – 29  30 – 39  40 – 49  50 – 59  
 60 – 69  70 – 79  80 or older

**How do you identify your gender?**  Female  Male \_\_\_\_\_

**What is the highest level of school you completed/ the highest degree you have received?**

Less than 9<sup>th</sup> grade      Some high school      High school graduate  
Some college      College graduate      Advanced graduate degree

**What, if anything, do you think would improve the Caregiver Respite Volunteer program?**


*If you have any friends or colleagues who might want to volunteer please include their names and phone numbers here so we can reach out to them.*

<b>First Name</b>	<b>Last Name</b>	<b>Phone</b>

<b>Additional Comments:</b>

*THANK YOU for taking the time to complete our survey!  
Please see your Volunteer Coordinator to collect your incentive.*



**CAREGIVER RESPITE PROGRAM  
CLIENT AGREEMENT**

Caregiver Respite Program of Lifespan provides non-medical volunteer caregiving for frail older adults to help them maintain their dignity and remain independent in their homes. We have volunteers from the local community who will provide support to you and your caregivers. Our volunteers are individuals you can trust, you can spend time with, and who will listen when you need it.

You will be provided services that you request, given what the program is able to offer and based on volunteer time, availability and skills. Our volunteers:

- Are not required to provide additional services.
- Cannot loan or give you any money or pay your bills.
- Cannot dispense medication, change bandages or clean wounds, or give other hands-on care.

Our volunteers have participated in formal training where they have been given basic information about illnesses that care receivers may be living with, and they have learned how to set limits and boundaries. They will not share your name or any information about you with people not involved with your care without your written permission.

The best way to contact your volunteer(s) is through program staff. Call the Caregiver Respite office at 244-8400 ext. 152 or 209. We will also be calling you occasionally to see how you are doing.

1. I understand the Caregiver Respite Program is a volunteer organization and while all reasonable efforts will be made to meet my request, services are not guaranteed.
2. I understand the program is donation-based but that I will not be denied services if I choose not to donate. There will be no payment requested or expected when services are provided.
3. I understand that I am free to stop participating in the program at any time.
4. I will make every effort to communicate my needs to Caregiver Respite Program.
5. I agree to hold harmless Caregiver Respite Program, its employees, agents and volunteers for any losses or damages incurred by me unless such losses or damages were the result of intentional or willful misconduct.

I have read the client agreement and understand its contents.

\_\_\_\_\_  
Caregiver/Receiver Name/Date

\_\_\_\_\_  
Witness Name/Date



*Lifespan Appendix # 7*

**Care Receiver Interest Survey**

Your Name: \_\_\_\_\_

Birthdate: \_\_\_\_\_ Birthplace: \_\_\_\_\_

Spouse and years married: \_\_\_\_\_

Schooling and past occupations: \_\_\_\_\_

Places you've lived: \_\_\_\_\_

Children and Grandchildren: \_\_\_\_\_

Influential Family Relatives/favorite person: \_\_\_\_\_

Favorite memories (holidays/vacations, family trips): \_\_\_\_\_

\_\_\_\_\_

Pets: \_\_\_\_\_

Personality Traits (outgoing, reserved, conversational, sedentary): \_\_\_\_\_

\_\_\_\_\_

Any special likes/dislikes (i.e. topics to avoid): \_\_\_\_\_

Other information to share that would be of help with matching a volunteer: \_\_\_\_\_

\_\_\_\_\_

ACTIVITIES: Please describe leisure interests.

Community activities/Entertainment (dining out, coffee/tea, shopping, religious/church involvement, library, public market, senior citizens, concerts/movies/museums, historical events/sightseeing, YMCA): \_\_\_\_\_

\_\_\_\_\_

Outdoor activities (walking/hiking, gardening, biking, bird watching): \_\_\_\_\_

\_\_\_\_\_





4. How helpful is the Caregiver Respite program volunteer? *(Mark one answer on each row.)*

	<b>Not at all Helpful</b>	<b>Somewhat Helpful</b>	<b>Very Helpful</b>
a) To you			
b) To your loved one			

5. What types of things does YOUR VOLUNTEER do? *(Mark one answer on each row.)*

WITH OR FOR YOUR LOVED ONE . . .	<b>Never</b>	<b>Occasionally</b>	<b>Frequently</b>
Share a meal or prepare food for him/her			
Read to him/her			
Take him/her on an outing			
Play cards or other games with him/ her			
Take him/her for a walk			
Provide transportation			
Friendly visiting/companionship			
<b>OTHER</b>			
<b>WITH OR FOR YOU . . .</b>			
Light housekeeping			
Yard works/snow removal			
Minor home repairs			
Run errands for you			
Provide listening/support			
<b>OTHER:</b>			

6. What else would be helpful to you as a caregiver? (Write in your answer in the box below.)

7. How good a match is your Caregiver Respite volunteer? (Mark one answer on each row.)

	Not a very good match	Okay	A good match
a) For you			
b) For your loved one			

8. Are you and the volunteer able to arrange mutual times and activities for the visits?

Rarely    Sometimes    Always

9. Please rate the promptness of your volunteer (check one)

Never late    Sometimes late    Often late    Always/Almost Always late

10. Would you say that having visits from your Caregiver Respite program volunteer has helped you reduce your stress? (check one)

No    Somewhat    Yes

11. Would you say that having visits from the Caregiver Respite Program volunteer has helped improve quality of life for your loved one? (check one)

No    Somewhat    Yes

12. Please rate the overall usefulness of the Caregiver Respite Program (check one)

Not useful    Somewhat Useful    Useful    Very useful

13. Have you taken the *Powerful Tools for Caregiver Class*? (check one)

Yes    No

Why not? \_\_\_\_\_

14. How helpful was the Powerful Tools for Caregiver class? (*check one*)

Not helpful    Somewhat helpful    Helpful    Very helpful    I never took the class

**About You:** Please provide the answers below that best describe you.

15. Which category below includes your age?

18 – 29    30 – 39    40 – 49    50 – 59  
 60 – 69    70 – 79    80 or older

16. Your gender:  Female    Male

17. What is the highest level of school you have completed or the highest degree you have received?

Less than 9<sup>th</sup> grade    Some high school    High school graduate  
 Some college    College graduate    Advanced graduate degree

18. What, if anything, do you think would improve the Caregiver Respite Volunteer program?


<b>Additional Comments:</b>

*THANK YOU for taking the time to complete our survey!*

# Caregiver Respite Program

## Final Evaluation Report

Submitted to:

**Ann Marie Cook, President and CEO**

**Cindy Steltz, Education Director**

Lifespan of Greater Rochester, Inc.

**Director of Aging Services**

**SCP Respite Coordinator**

The Community Place of Greater Rochester, Inc.

Submitted by:

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September 2018



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## Caregiver Respite Program: Final Evaluation Report Executive Summary

The Caregiver Respite Program is a collaborative effort of Lifespan of Greater Rochester, Inc., and The Community Place of Greater Rochester, Inc. It was established to provide services to caregivers and their loved ones (care receivers), individuals with cognitive impairment or early dementia who are living in the community. In its first two years (2013-14, 2014-15) the Caregiver Respite Program established collaborative practices and over the full five years, the Respite Care Program has become institutionalized and through the partnership is reliably able to produce promised outcomes despite the considerably complex and challenging nature of the work.

As the program has reached long-term duration, which adds to its value to clients, program staff have taken on additional requirements to continue balancing maintenance of relationships with recruiting, training, record-keeping, and re-assignment for an ever-growing and changing population. Additionally, the program at Lifespan has added additional collaborative channels as Caregiver Respite Program staff interact with Lifespan's Finger Lakes Caregiver Initiative (FLCI) staff and have taken on Project Hope with the University of Rochester.\* Throughout the five years, the program has continued to use established collaborative practices, delivered on its objectives to recruit, screen, train and match volunteers with caregivers/care receivers, and to support their ongoing efforts while promoting reduced stress for caregivers and maintaining/enhancing quality of life for care receivers. Using similar but customized, complex strategies including care receiver assessment and volunteer/caregiver matching, the partners have continued to address a critical community need and to inform replication of volunteer respite strategies through other initiatives. Though recruitment and oversight for the program are always demanding for both partners, the number of trained and capable volunteers has consistently met or exceeded targeted levels, new volunteers have been recruited each year, substantial outreach to caregivers has occurred and new viable matches were made while existing matches and volunteers continued to be supported for multiple years in many cases. Additionally, substantial levels of service have been delivered, the program continued to grow, and feedback from volunteers and caregivers has been overwhelmingly and very consistently positive. The Caregiver Respite Program has been the subject of comprehensive evaluation (including retrospective data analysis since spring 2015). Key Findings from the evaluation through spring 2017-18 include the following.

- **Through all five years, volunteers ensured that respite happened, and the Lifespan and Community Place partners ensured that volunteers were recruited, cleared, trained and supported** as they provided services. Over the five-year period the partners worked with more than 244 potential volunteers. This included both male and female volunteers and those who came from the city and the neighboring towns. About 11% of the volunteers were African

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\* Project Hope is a collaborative venture between the University of Rochester and Lifespan that seeks to provide volunteer opportunities for persons who feel isolated from others, lack companionship or feel left out, as a strategy to help both caregivers and care receivers.

American, 7% were Hispanic/Latino, 81% were Caucasian. Most active volunteers were in their 60s and 70s (the average age overall was 66).

- **The program continued to grow.** Due to both continued recruitment and longevity of matches there was a 21% increase in the number of volunteers involved (Year 5 compared to Year 4), and there were many more active matches in Year 5 (+20%)
- **Caregiver needs were diverse.** Many of the caregivers were contemporaneous with the volunteers (in their 60s and 70s), but some were younger and some were older, including several who were 90 or older. More than 70% of the caregivers were female, many caring for a spouse or an aging parent, and many had additional family members such as adult children who also helped with caregiving responsibilities (and required additional respite care attention).
- **During Year 4 and Year 5, Lifespan began to collect additional data about companion caregivers.** A total of 40 caregivers, usually spouses, have additional family-based assistance, mostly grown children. They are involved and supportive, but most decisions rest with the primary caregivers (often informed by the care receiver).
- **Care receivers had multiple needs.** The care receivers were older (many were in their 80s or 90s). Slightly more than half (58%) were female and most (76%) lived with their spouses or other family members. In addition to care receivers with Alzheimer's (including early onset Alzheimer's), there were care receivers with Lewy Body dementia, FT dementia and other early dementia-related challenges such as confusion and memory loss. Though most were mobile, they were medically frail in addition to their dementia. In longer-running matches, the challenge of visiting with increasingly diminished care receivers can become increasingly difficult as illustrated by the following comments.
- **Caregiver Respite Program staff continue to use effective strategies for accomplishing widespread respite. Recruitment is ongoing and staff continued to conduct assessments and offered scheduled training, while also providing additional supports when needed and new matches for cases that discontinued.** Overall across the five years, more than 50,841 hours of respite were provided. A total of 336 families and 207 volunteers accessed the Caregiver Respite Program.
- **Many successful matches were made and sustained with volunteers and caregivers from both partner agencies.**
  - More than 244 potential volunteers accessed the Caregiver Respite Program, 207 of those prepared for or provided respite, including 170 who served. This included: 98 available volunteers at the end of Year 5, 19 others on-hold (who have not officially retired, but did not provide respite in 2017-18), and 3 who were in-process, 26 volunteers who completed all training but then decided to pursue other callings, and 61 volunteers who had retired after service.
  - Almost all of the 336 caregivers who accessed Caregiver Respite Program were assessed, and in most cases (76%) matched with a volunteer (an additional 4% were waiting for a first match at the end of Year 5).

- Half (50%) of the Lifespan volunteers with cases opened by 5/31/2017 had matches that lasted one-year or longer, several extended more than two years. There continued to be new matches each year of the program.
- **The Caregiver Respite Program retained many volunteers – one-third of Lifespan’s volunteers have been with the program since the first or second year, 80% have been with the program more than a year. The partners clearly continued to manage re-assignment so that training and long-term effort were maximized to sustain respite options.** Many phone calls were made to volunteers, potential volunteers, caregivers, and caregiver companions to keep the process operational. Additionally, regular meetings were conducted with volunteers to provide continued training and support. Volunteers reported via the survey that they felt supported and their training was sufficient. Increasing numbers of volunteers continued to take on matches after closing a match and multiple volunteers had more than one open match.
- **Available data showed that matches closed mostly due to changes in the care receivers’ conditions.** This along with new challenges and changes in circumstances (e.g., health issues, moving), for the volunteer population were confirmed by staff as primary reasons for matches closing during Year 5.
- **Feedback from volunteers about their volunteer experience was consistently very positive.** Almost all volunteers rated their volunteer experience as *meaningful/very meaningful* and agreed they were *satisfied/very satisfied* with their experience. Despite many having now served multiple years, all but a few respondents reported they would continue volunteering and would recommend Lifespan or Community Place to others.
- **Volunteers were involved in several different activities with care receivers and caregivers.** Most commonly they conducted friendly visits with care receivers, chatting or sitting together to watch TV. Almost two-thirds of the volunteers also reported they shared or prepared meals, or went on outings or walks at least *occasionally*. Caregivers confirmed volunteers’ reports. **It was also clear from the responses that volunteers focused their efforts on interactions with care receivers, but also frequently did tasks, especially listening, directly with/for caregivers.**
- **Caregivers used their respite time, mostly to take care of family needs and to take some breaks.** Most reported that they spent the time doing errands or shopping. Many also indicated they used the time to just relax on their own, to take care of their own medical issues, or to meet up with family or friends. Many fewer caregivers indicated they used the time for personal caretaking such as visiting the gym or attending a class.
- **Lifespan regularly offered the Powerful Tools for Caregivers class to help caregivers manage their stress and enhance their personal situations. Positive feedback about the classes and substantial increases in skill development were reported.**
- **There was continued awareness of caregiver respite services available through Lifespan and Community Place and community residents are accessing NY Connects as a strategy to learn about respite options. Each year, multiple advertising and outreach efforts were conducted.**
- **Across all five years, feedback from volunteers and caregivers about program and family outcomes has been very consistently positive. For 2017-18:**

- Almost all volunteers (87%) and most caregivers (88%) rated the program as *useful* or *very useful*.
- More than three-fourths of volunteers thought their matches with both caregivers and care receivers were *good*. This was confirmed by caregivers. Some matches are better than others and there remain challenges such as scheduling and caregiver/ care receiver willingness to participate
- Almost all volunteers (98%) and all of their associated caregivers (100%) rated caregiver respite as *somewhat* or *very helpful* for both caregivers and care receivers (most rated Caregiver Respite Program as *very helpful*).
- Almost all volunteers (96%) reported that they had helped to reduce caregiver stress at least *somewhat* and caregivers (96%) confirmed volunteers' reports.
- Both volunteers (94%) and caregivers (96%) thought the Caregiver Respite Program helped improve the quality of life for the care receiver.

### *Issues for Further Consideration*

1. *Maintain the existing program and the many sustainable strategies that were developed to support caregiver respite. Continue to support effective collaboration between partner organizations. Continue to focus on productive volunteer recruitment strategies including ongoing support and evaluation of Project Hope. Many volunteers have multiple years of service and will continue to phase out of their efforts as the many retired volunteers have done.*
2. *Continue program support especially for the matching process and working to rapidly place volunteers and maintain matches. Make sure all caregiver and volunteer requests for information or support are addressed as quickly as possible. Continue informing replication efforts.*
3. *Continue working to ensure as many trained volunteers as possible are actively providing respite services. Provide extra support to those in very new or those in longer-term matches as needed. Continue to do whatever is needed to support and sustain existing matches. Make sure volunteers have continued support, possibly by learning from other volunteers, to help them work effectively with care receivers.*
4. *Continue to focus on outreach, recruitment and retention of volunteers, and outreach to caregivers to participate in caregiver training. Powerful Tools for Caregivers training results show very promising results. Continued study of what is needed to increase participation is strongly advised.*
5. *Be sure to continue to factor in the need for volunteers to take time off between difficult matches, but to stay connected so they return to provide respite for multiple cases. Investigate whether volunteers "On-Hold" can be returned to active service, re-assign matches where needed and track match status fully.*
6. *Review again whether current staffing levels at each agency are sufficient to manage the volume of project operations.*
7. *Continued attention to complete and accurate record keeping is advised. Both partner organizations are encouraged to continue reviewing coding and data management regularly, and to ensure that Community Place data is fully restored going forward.*

## I. INTRODUCTION

The Caregiver Respite Program is a collaborative effort of Lifespan of Greater Rochester, Inc., and The Community Place of Greater Rochester, Inc. It was established to provide services to caregivers and their loved ones (care receivers), individuals with cognitive impairment or early dementia who are living in the community. Through the program it is further intended that the quality of life will be preserved and perhaps enhanced for both caregivers and care receivers. In its first two years, the Caregiver Respite Program established collaborative practices and during the following years, through May 2018, continued to consistently deliver on the objectives to recruit, screen, train and match volunteers with caregivers/care receivers, and to support their ongoing efforts while promoting reduced stress for caregivers and maintaining/enhancing quality of life for care receivers.

### **Partners in Caring/ Senior Companion Overview**

As stated in their grant agreement, Lifespan of Greater Rochester, Inc., (Lifespan) in collaboration with The Community Place of Greater Rochester, Inc., (Community Place) sought to develop and implement a comprehensive caregiver respite program in Monroe County for families taking care of a loved one with dementia. The program is funded by the Rochester Area Community Foundation with a grant from the Helen L. Morris Foundation. The objective of the umbrella Caregiver Respite Program is to bring trained volunteers to help caregivers of those struggling with mild cognitive impairment or early stages of dementia. Volunteers are expected to provide respite services including friendly visits and outings as well as any of the following: transportation to appointments, shopping or errands, light housework, yard work or minor home repairs or occasional meal preparation. As they had during all prior years, for 2017-18, both Lifespan and Community Place recruited volunteers for respite services and they provided screening, comprehensive training and oversight for volunteer services (including stipend management in the case of Community Place volunteers). In addition, though their programs have some different features (see Year 2 Evaluation Report), both organizations also conducted and managed a comprehensive matching process bringing volunteers and families together (including comprehensive care receiver geriatric assessment). Overall goals continued to be to raise awareness about respite options in the Greater Rochester community, to provide ease of access to monitored/supported services (one call to Lifespan's NY

Connects, formerly Eldersource, from those not already accessing services at either Lifespan or Community Place initiates assessment and triage), to support ongoing respite services to families in need, to help maintain/enhance the care receiver’s quality of life, and most importantly to provide respite and reduce caregiver stress. (See Appendix 1 for additional details about the program and the roles of both Lifespan and Community Place.)

**Intended Program and Client Outcomes**

- Provide comprehensive volunteer recruitment, screening and training.
- Manage and use program data to inform program oversight.
- Increase awareness of respite services as evidenced by volume of and response to outreach.
- Increase the number of people receiving respite care in Monroe County.
- Increase the number of volunteers providing respite services and continue supporting those actively involved.
- Decrease caregiver stress, contribute to improved quality of life for care receivers, as reported by caregivers.

**Specific Targets and Outcomes Through 2018**

Caregiver Respite Program partners set internal goals and, as shown below, have exceeded targets.

<b>Totals for 2017-18</b>	<b>TOTAL</b>	
# of NY Connects calls/walk-ins	3392	
# of new volunteers recruited/trained	74	
# of new matches made	70	
# of volunteer hours	13,399.15	
<b>Cumulative to date since inception</b>	<b>GOAL</b>	<b>TOTAL</b>
# of volunteers recruited and trained	145	<b>207</b>
		<b>336*</b>
# of Families/Caregivers served	200	

**Important Definitions**

**Caregiver Respite Program**

**Respite Volunteer:** trained individual who visits the care receiver to provide support to him/her and the caregiver, so the caregiver can attend to other needs and interests.

**Caregiver:** usually a spouse or close relative of the care receiver who often lives with and is responsible for the care receiver’s well-being.

**Caregiver Companions:** additional individuals such as grown children or other family members who provide support to the family.

**Care Receiver:** the loved one with mild cognitive impairment or early stages of dementia.

## Caregiver Respite Program Evaluation

The Caregiver Respite Program was the subject of a continued, multi-year program evaluation corresponding to program implementation Year 1, 6/1/13 – 5/31/14 through Year 5, 6/1/17 – 5/31/18. Each year, multiple evaluation questions were addressed and multiple evaluation strategies were used to track and summarize program outcomes.<sup>2</sup> Evaluation questions included the following:

- Who participated in the program (caregivers, care receivers, respite volunteers)?
- How and to what extent did Caregiver Respite collaborators meet their desired program outcomes?
  - Increase and support the number of trained volunteers using a dual strategy.
  - Match sufficient numbers of trained volunteers with caregivers/care receivers.
  - Increase awareness of the benefits of respite and increase awareness of caregiver respite as evidenced by sufficient and regular use of respite services.
- To what extent did the program help to reduce caregiver stress and contribute to improved quality of life for the care receiver?

For this report, evaluation questions were again addressed using multiple strategies including:

- Collection and analysis of all extant data including intake information for volunteers, caregivers and care receivers; monthly reports, and training feedback.
- Collection and analysis of volunteer and caregiver feedback through customized surveys delivered online or in hard copy for volunteers and online and by phone with caregivers (spring 2015 through spring 2018).
- Annual interviews with key collaborators from both Lifespan and Community Place.

Year-end evaluation strategies also included full independent review and aggregation of all individual volunteer and caregiver records from both agencies for the five-year period using data extracted from their systems. During the 2017-18 program year, Lifespan continued to use its new data management system which facilitated both program oversight and evaluation; as a result of staff turnover and systems challenges, Community Place data reported was somewhat limited.<sup>3</sup> Evaluation results are shared annually through this final summative, over-years report.

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<sup>2</sup> Originally a comprehensive research project was planned for the Caregiver Respite Program, but it was determined that evaluation would better support reporting and program decision-making needs. The evaluation, initiated during Spring 2015, focuses on all five years of the project.

<sup>3</sup> Community Place was only able to provide a list of all Volunteers, with status and Care Receivers for 2017-18. No Caregiver updates, or Care Receiver details were available. Most cases however, were continued from prior years so all but any new cases include complete data about Volunteers, Caregivers and Care Receivers.

## II. PROJECT FINDINGS

As they have since 2013-14, Lifespan and Community Place worked collaboratively in 2017-18 to raise awareness about respite options and to ensure that volunteers were recruited and trained to provide respite services for the targeted population. Both agencies continued to provide oversight and support and as shown in this section, multiple volunteers were recruited, including 7 in 2017-18 working as part of Project Hope,<sup>4</sup> new matches were made, ongoing matches were supported and respite service was provided. Further, both volunteers and caregivers continued to provide positive feedback about important outcomes. The following sections provide findings about how many volunteers provided respite services over the five-year period, who the volunteers were, who they served, how much time they spent providing respite, what they did, and who they provided services for (both care receivers and caregivers). Section II ends with summaries from the four rounds of surveys of volunteers and caregivers regarding program outcomes and is followed in Section III with a summary of key findings through 2017-18 and identification of issues for further consideration.

### A Note about Data

Descriptive data about volunteers, caregivers and care receivers from Lifespan and Community Place were secondarily aggregated and analyzed for this report. Surveys were also conducted each Spring 2015 – 2018, and both Caregivers and volunteers answered specific questions and shared comments about the Caregiver Respite Program. Quotes from volunteers and caregivers are shown in the report to illustrate key findings and to share the voices of the real people involved in caregiver respite. All data have been aggregated to show independently determined longitudinal results.

*It was very important for me to reach out to people in the community who could benefit from seeing a friendly face. Volunteer, 2017-18*

*I feel so useful to the caregiver AND to the client. They have been effectively cut from their friends. I am someone who comes to see them regularly. Listens to them and takes them for rides. Volunteer, 2017-18*

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<sup>4</sup> Project Hope is a collaborative venture between the University of Rochester and Lifespan that seeks to provide volunteer opportunities for persons who feel isolated from others, lack companionship or feel left out, as a strategy to help both caregivers and care receivers.

## Volunteers, Caregivers and Care Receivers

Volunteers ensure that respite happens, and Lifespan and Community Place ensure that volunteers are recruited, cleared, trained and supported as they provide services. Over the five-year period, Lifespan/Community Place partners have worked with more than 244 potential volunteers including 207 who have been fully vetted.<sup>5</sup> This includes 159 who served through Lifespan and at least 48 who served through Community Place. Between 2016-17 and 2017-18 there was a 21% increase in the number of Volunteers recruited/maintained by the partners. Volunteer characteristics are detailed in Table 1 below.

**Table 1: Characteristics of Volunteers, 2013-14 through 2017-18**

	Total* n=207
<b>AGE of ACTIVE VOLUNTEERS</b>	
Less than 60	23%
60 – 69	38%
70 – 79	29%
80 – 89	10%
<b>GENDER</b>	
Female	72%
Male	28%
<b>RACE/ETHNICITY</b>	
African American	12%
Caucasian	81%
Hispanic/Latino	6%
Other	1%
<b>LOCATION</b>	
Rochester	57%
Suburbs	43%
<b>EDUCATION LEVEL **</b>	
Less than high school	11%
High school	23%
Some college	16%
College Grad/Advanced degree	51%

\* Note that background data for 15 Community Place volunteers was not reported.

\*\* Education data for Lifespan are estimates based on survey responses.

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<sup>5</sup> In addition to the 159 volunteers who have fully engaged with Lifespan, an additional 37 individuals began but did not complete volunteer application/training. Training covers aging, dementia and volunteer support information.

Among the 159 volunteers who worked with Lifespan, 78 were active as of May 31, 2018 including 53 who were actively providing respite, 18 who had worked with one or more families but were waiting for a new match, 4 new recruits who were fully trained and waiting for their first match, and there were 2 volunteers in the process of being trained and fully vetted. As the total numbers of volunteers working with Lifespan increased, (Year 5 compared to Year 4), so did the proportion of volunteers actively providing respite. Among the 48 volunteers who worked with Community Place, 18 were active as of May 31, 2018, including 4 volunteers waiting for a first assignment and 1 waiting to be re-matched (see also the following section for more details about volunteers and caregiver/care receiver matches).

Table 1 also shows other background information about Caregiver Respite Program volunteers.

- Most of the active volunteers were 60 or older including 38% who were between the ages of 60 and 69 and 29% who were between the ages of 70 and 79. Eight volunteers were in their 80's.
- Over the five years, most volunteers (72%), were female, but male volunteers were both involved and requested for the many male care receivers. Though not shown in the table, Lifespan's male volunteer population increased to represent 42% of the active volunteers by 2017-18. All but two of the active Community Place volunteers were female.
- Based on estimated race/ethnicity data, the volunteer population reflected community race/ethnicity statistics. Most volunteers were white (81%), about 11% were African American, and about 7% identified as Hispanic/Latino. (Most African American and Hispanic/Latino volunteers were affiliated with Community Place. One active Lifespan volunteer is East Asian).
- Almost half of the volunteers (43%) lived outside of the city in one of the neighboring towns (e.g., Fairport, Henrietta, Penfield, Pittsford, Webster), and all others (57%) reported addresses in Rochester (all Community Place volunteers live in and in all but a few cases work with caregivers who live in the city of Rochester).
- It is estimated that about two-thirds of the volunteers had educational histories that included at least some college.

Volunteers learned about the need for volunteers and the opportunities to be of service through several channels. This included presentations and direct referrals made by Lifespan and Community Place staff, the newspaper, friends/family and other volunteers, events, houses of worship and via the Internet.

**Table 2: Characteristics of Caregivers**

	Total n=281
<b>AGE of CAREGIVERS IN ACTIVE MATCHES*</b>	
Less than 60	38%

60 – 69	9%
70 – 79	27%
80 – 89	20%
90 or older	5%
<b>RACE/ETHNICITY</b>	
African American	16%
Caucasian	70%
Hispanic/Latino	14%
Other	<1%
<b>GENDER</b>	
Female	73%
Male	27%
<b>RELATIONSHIP OF PRIMARY CAREGIVER</b>	
Spouse	49%
Son or Daughter	41%
Family Member	7%
Other	3%
<b>CAREGIVER ARRANGEMENTS</b>	
Percent with companion caregivers (Lifespan only)	14% (n=40)
Percent who live with Care Receiver (Lifespan only)	33%

\* Age data for caregivers associated with Community place were not reported. Race/ethnicity data were missing for multiple caregivers associated with Lifespan.

Caregiver records for Community Place were not updated in 2017-18; totals and percentages reflect only available data including possible slight under/over counts. Most cases continue.

Data were also captured to describe Caregivers as shown in Table 2. Background characteristics of volunteers and caregivers were similar. Many caregivers (Lifespan only) were between 60 and 79, about 38% were less than 60, but there were substantially more caregivers than volunteers who were 80 or older. Like the volunteers, most caregivers were female (73%, although as shown in Table 3, many care receivers were male). Summarization of available race/ethnicity data showed that most caregivers were white (70%), about 16% were African American, and about 14% identified as Hispanic/Latino; the proportion of non-white caregivers has been increasing over the five years. (Most African American and Hispanic/Latino caregivers were affiliated with Community Place, but updates on caregiver data for Community Place for 2017-18 were not available.) In terms of relationships, somewhat less than half (41%) of the caregivers were adult children of the care receivers and about 49% were spouses of the care receiver. The rest were other family members (e.g., siblings, grandchildren)

During years 3 through 5, the partners have been collecting information about caregiver companions (Lifespan only) and caregiver living arrangements. Assessments showed that many (33%) of the caregivers

lived with the care receiver, but about one-quarter of care receivers were living on their own (see also following text box and Table 3). A total of 40 of the 232 caregivers affiliated with Lifespan reported having caregiver companions (questions about companions were added to assessments in 2015-16), almost all of whom are the grown children of the primary caregiver. Though data are limited (Lifespan only), available reports showed that even when there are caregiver companions, most decisions and responsibilities fall to the primary caregiver, with care receivers sometimes still involved.

**Where did Care Receivers Live? (2017-18, n=140)**

- A total of 66% owned and lived in their own home or apartment (mostly with caregivers).
- A total of 26% lived in the single home or apartment of a relative.
- About 8% lived in units in senior residences.
- Two were in assisted living facilities.

**Based on assessment of Care Receivers working with Lifespan only.**

Both partner organizations also provided information on care receivers (see table 3). As shown, the care receivers were older (many in their 80s or 90, the average age of care receivers in active cases with Lifespan was 79 and with Community Place, 80). More than half (58%) were female and most (77%) lived with their spouses and/or other family members. Though most were mobile, they were medically frail in addition to their dementia (see also the appendix for a list of other recorded medical challenges faced by care receivers). Both Community Place and Lifespan reported that some of the care receivers were living in homes with safety challenges.

Since project inception, the partner organizations conducted geriatric assessments of all potential program participants to determine what their interests and needs were and to ensure they could match them with volunteers that would be a good fit. Both Lifespan and Community Place continue to look at the family's location and characteristics, and the volunteers' wishes and availability and match based on what should work. Most Lifespan volunteers only worked with one family at a time, though as described in the next section (and Appendix 2), many volunteers ultimately worked with multiple families. The Community Place volunteers worked a minimum of 15 hours per week (most did 20). For both Lifespan and Community Place, scheduling visits continues to be challenging, though efforts at Lifespan to reduce the time between recruitment and placement have eased scheduling challenges somewhat.

**Table 3: Care Receiver Profiles**

	TOTAL n=336
<b>AGE</b>	
Less than 60	2%
60 – 69	9%
70 – 79	32%
80 – 89	42%
90 or older	16%
<b>GENDER</b>	
Female	58%
Male	42%
<b>LIVING ARRANGEMENTS</b>	
Alone/independent	23%
With spouse	28%
With spouse and/or other family	48%
Other	1%

Caregiver records for Community Place were not updated in 2017-18; totals and percentages reflect only available data including possible slight under/over counts. Most cases continue.

*My care recipient doesn't really ask much although I think she finds life very worthless at this point because it is stale, confusing and there is no joy. She has little stimulation. I understand it can get this way with dementia. While the family visits [often] to check on their Mom, it is meaning little to her at this point. She wants more care for herself and says she should be in a nursing home. . . .When I visit, I try to do something with the recipient that will take her mind off of the drudgery of her living situation. I try to do something that will stimulate her brain or take her out to find some moments of beauty or joy. We will go for a walk to see what is blooming, go to George Eastman house to see a new place, listen to some music, play a game . . . . When I visit, she is really bent on complaining about how her family wants her to be miserable so they've put her in this place she doesn't recognize and not giving her the care she needs. I do think she is delusional on this account but it is getting hard to move beyond this. At the end of many visits we have had, she has thanked me greatly and said this was a wonderful way to pass the time. I could also tell from what we did, that she experienced a nice change and some real pleasure from the outing. I understand that since I am retired that I have some flexible time to contribute to this when I visit so we have the option to go somewhere. Volunteer 2017-18.*

## Level of Service

During each of the five years, the partners worked to get volunteers matched with caregivers who needed assistance. As described in the previous section and prior reports, the matching was challenging. In addition to the match process, staff must also recruit volunteers, provide rigorous screening, and comprehensive training on Alzheimer's disease and dementia and the standard practices of volunteering (see also additional details, Appendix 1). To date, match status, and reports from caregivers and volunteers via surveys continue to show many successful and long-term matches have been made with volunteers and caregivers from both Community Place and Lifespan. Though shorter-term matches also occur (due mostly to changes in care receiver health, and sometimes changes in volunteer circumstances), and some caregivers were never matched, more than half of the matches opened by 5/31/2017 lasted one-year or longer and several matches extended two years or more. By 5/31/2018 there were also many new matches that started during Year 5 at both partner agencies.

As stated in the three-year evaluation report (August 2016), in order for Caregiver Respite Program service to proceed, several factors must be in place:

- The care receiver had to fit the targeted profile (i.e., have dementia or be in the early stages of Alzheimer's disease).
- There had to be trained and available volunteers.
- The match had to work for both parties (i.e., the caregiver has to fully agree to and facilitate the visits and the volunteer had to schedule and conduct them; care receivers had to not resist).

In multiple cases, respite was provided only for relatively short periods of time as care receivers required more care or sadly, passed away. There have also now been multiple cases at both agencies where serious health concerns, or end of life have forced volunteers to close cases. The program operators at both Lifespan and Community Place have continuously recruited, conducted assessments and offered scheduled training, while also providing additional supports when needed for ongoing matches, and new matches for cases that were discontinued. As of May 31, 2018, a total of 207 trained volunteers have been engaged in the Caregiver Respite Program including many who are now retired after having provided service, as well as newer volunteers and even a few who are waiting for a first match. Additionally, a total of 327 registered caregivers have sought respite (more than 360 including CG companions). While some cases were diverted (see Note 4) and some were still waiting for a first match with recently recruited

volunteers, most of the caregivers received regular assistance (3 – 4 hours per week for Lifespan volunteers, several hours per week for multiple clients for Community Place volunteers).

**Case Status**

This section on case status presents data about volunteer status, match requests and match status as of May 31, 2018, for the 2013-14 through 2017-18 time periods (see Table 4 and Appendix 2 for additional details).

**Table 4: Case Status Summary, 2013-14 through 2017-18**

<b>VOLUNTEER STATUS</b>	N=207	
Active Volunteers	71	34%
Volunteers Waiting to be Re- Matched	19	9%
Waiting for a First Match*	8	4%
Volunteers in Process (Lifespan only)	3	1%
On-hold	19	9%
Completed training but did not provide respite	26	13%
Retired volunteers	61	29%
Combined total hours of Respite, Year 2 - Year 5	50,145 hours	
<b>CAREGIVER/ CARE RECEIVER MATCH STATUS <sup>6</sup></b>	N= 336	
<b>Active/in process</b>		
Active as of 5/31/18	78	23%
Waiting for re-match	4	1%
Waiting for 1 <sup>st</sup> match	14	4%
On Hold	6	2%
<b>Permanently closed</b>		
Matched	153	46%
Never Matched	70	21%
<b>Unknown</b>	11	3%

Volunteers from both partner agencies served many families throughout the five-year period. As matches ended, volunteers waited to be reassigned with new families, retired from the program, or suspended their involvement if necessary. Caregiver respite always involved multiple complexities including readiness

<sup>6</sup> Note that in each year a small number of additional cases were diverted due to inappropriate fit (<20/year). Community Place does not record data on diverted cases. The number of caregiver cases shown in Table 4 excludes diverted cases. A total of 6 matches at Community Place do not include a caregiver. **Additionally, not all caregiver or care receiver records for Community Place were recorded. Totals reflect only available data and may represent slight over/under counts. Percentages are based on available data.**

of the caregiver, and fit for both volunteer and caregiver/care receiver. As stated in prior evaluation reports, the work was emotionally challenging and sometimes personally difficult. These realities characterized the Caregiver Respite Program throughout all five years and are expected to continue. As shown in Table 4, as of May 31, 2018, 71 Caregiver Respite Program volunteers were actively serving families, 30 were in the pipeline waiting to be assigned a first match (8), to be re-matched (19) or working through the verification process (3 Lifespan only). Among the active volunteers in 2017-18, more than 1,117 hours/month of respite was provided (almost double the amount recorded in 2016-17). Though hours were not tracked during Year 1, as stated above a total of 50,145 hours were logged for Year 2 through Year 5 combined (13,399 logged in 2017-18).

Not all volunteers sustained their participation throughout the initiative. Among the 207 volunteers there were 106 who, as of 5/31/18, were no longer actively preparing to or providing respite: including 61 who had retired after having provided much respite to others, 19 who were on-hold due to their own health or other changes in circumstances (e.g., moving), and 26 who elected after completing all training to pursue other callings. As stated in the Year 3 and Year 4 evaluation reports, volunteers usually required some downtime between cases that closed as they mourned the death or decline of the care receiver (for more details on cases and timing, see Appendix 2). Throughout Year 5, the Caregiver Respite Program continued to prepare, retain and retire volunteers, and clearly could manage re-assignment so that training and long-term effort were maximized to sustain respite options. Volunteers reported via the survey that they felt supported and their training was sufficient (see final section).

*[My care receiver] enjoys singing so I brought cd's from the library, observed which songs he liked, and then I printed out the lyrics. He enjoys a lot of Frank Sinatra songs and we have a great time singing them together. I call up the Youtube version on my phone so we can have a music accompaniment with them. The hand-made booklet has about 15 songs in it. Now I am exploring some Mitch Miller songs for him to sing. Volunteer 2017-18*

*We meet at YMCA. Caregiver works out. [Care receiver] and I walk the track, have coffee, talk, watch children playing/swimming, do puzzles, sing. Whatever he feels like doing. He's in charge. Volunteer 2017-18*

Caregiver Respite Program.<sup>7</sup> This included 255 requests for assistance (cases), where respite was at least “in process,” and 81 that were closed without any volunteer match having been made. For those cases

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<sup>7</sup> In addition to the cases described above there were at least 35 cases through 2016-17 that were not accepted as the care receiver was not a good fit for the program (only Lifespan tracked case diversion information but it is likely that some additional cases at Community Place were also referred elsewhere). Diverted cases were no longer tracked after the new system was implemented. *Case records for caregivers were not updated for Community Place*

that were opened, geriatric assessments were conducted to determine eligibility and volunteer match preferences and to initiate respite. For evaluation purposes, all requests were reviewed and case status was determined (see Appendix 3 for definitions regarding status).

As shown in Table 4, most full requests from caregivers (76%) resulted in respite. This included the following:

- A total of 78 cases (23%) that were active as of 5/31/18.
- A total of 4 cases (1%) that were waiting for a re-match and 14 cases (4%) that were waiting for a first match.
- A few cases (6) that were on hold due to caregiver or volunteer issues (2%).
- A total of 153 cases (46%) that were closed (after respite had been provided).

Some requests for respite were not satisfied: a total of 70 cases (21%) closed without a match ever having been made and information about 11 others was not recorded (3%). Throughout the five-year period, all of the management of the respite cases was overseen by staff at Lifespan and Community Place. Further, with the exception of cases diverted, most of the cases that staff managed were “active” cases at some point in time and for some duration, and all required staff oversight as assessment and matching and training were conducted and support was provided. Multiple phone calls were necessary to volunteers, potential volunteers, caregivers, and caregiver companions to keep the process operational. Additionally, at both Lifespan and especially at Community Place, regular meetings were conducted with volunteers to provide continued training and support. (Community Place staff also reviewed timesheets and made stipend payments, and both organizations made sure volunteers got mileage reimbursement and tracked hours of service.)

Over the five-years, both Community Place and Lifespan Caregiver Respite volunteers had multiple experiences. At Community Place, many volunteers saw more than one care receiver during the week – either at their homes, or at the community center,<sup>8</sup> in an effort to get up to 15 hours per week to fulfill employment requirements/options. While most Lifespan volunteers only had one active case at a time (and had only served one family), many had multiple cases over the five years. At all times, both

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for 2017-18. Though most cases continue, there were a few new caregivers who were not counted at all and a few care receivers whose background information was not recorded.

<sup>8</sup> As noted in prior evaluation reports, some of the Community Place volunteers accompanied their care receiver who had dementia to a Senior center. They picked them up at home making sure they were dressed and ready for the day and brought them to the center. They stayed with the care receiver who often couldn't navigate the center and activities on their own. Then they got them back home. In a few cases this allowed the caregiver to actually go to work.

Community Place and Lifespan staff were overseeing multiple volunteer/caregiver – care receiver relationships. In their own words (see below and the appendix) caregivers clarified that the process and the respite opportunities were valued.

**Responses to the survey questions about activities and what is helpful.**

*I am able to enjoy a hobby, golf with friends and know that someone is there to be with him, get his dinner and stimulate his mind. She is very dependable and I don't have to worry about leaving him alone for the time I am gone. Caregiver, 2017-18*

*It gives me a break and lets my hubby have fun. Caregiver, 2017-18*

*Our volunteer is so wonderful. I am very grateful for him. He is a mental life saver Caregiver, 2017-18*

*I can't place a value on this service. For us it is priceless. Caregiver, 2017-18*

*The care receiver is soon to be 90 years old and his wife is 85. She enjoys getting out for lunches, some shopping and some Dr. appts, so, since I live within 2 miles of them it is easy to set up some times so she can get some time away. Volunteer, 2017-18*

## Volunteer Services

Across the five-year program period volunteers performed different kinds of tasks when they were visiting care receivers and caregivers. The major focus of their work was to provide friendly visits to the care receiver, and to listen to and assist the caregiver when needed. To obtain direct reports from volunteers for the evaluation, we asked them survey questions each spring (2015 through 2018, n=143) about their experiences overall and about their specific work with individual care receivers/caregivers (n=168). Table 6 shows a summary of volunteer assessments of their work.

**Table 6: Volunteer Services**

<b>% of volunteers who reported that . . .</b>	<b>ALL RESPONDENTS n=143</b>
They were <i>satisfied/very satisfied</i> with their experience	99%
Their volunteer experience is <i>meaningful/very meaningful</i>	93%
They were <i>prepared/very prepared</i> to take on their volunteer work*	93%
Their training was <i>helpful/very helpful</i>	91%
The support they receive from their agency is <i>helpful/very helpful</i>	91%
They need more training	16%
They are <i>likely/very likely</i> to continue volunteering for Caregiver Respite Program	92%
They are <i>likely/very likely</i> to recommend Lifespan or Community Place to others as a place to volunteer*	98%
<b>% of caregivers (n=82)** who reported that . . .</b>	
They are <i>always</i> able to arrange meetings	83%
Their volunteer is always on time	95%

\* A total of 168 surveys were answered by the 143 volunteers as many of them had more than one volunteer experience over the five years of the initiative. Items identified with an \* above are questions that were asked in reference to a particular volunteer experience.

\*\* Most responding caregivers were associated with volunteers from Lifespan.

It can be seen in the table that feedback from the volunteers was very positive, and that volunteers thought their work was productive. Specifically,

- A total of 99% of volunteers reported they were *satisfied/very satisfied* with their experience.
- A total of 93% of volunteers reported that their volunteer experiences were *meaningful/very meaningful*.
- A total of 91% of volunteers indicated the training they received was *helpful/very helpful*.
- Almost all volunteers (91%) agreed the support they received from their agency was *helpful/very helpful*, and almost everyone (93%) said they were *prepared to take on their volunteer work with the specific families they served*.
- Further, a total of 92% of the volunteers said they were *likely/very likely* to continue volunteering for the Caregiver Respite Program and 98% said they were *likely/very likely* to recommend Lifespan or Community Place to others as a place to volunteer.
- Most caregivers who answered the survey reported they could *always* arrange meetings with their volunteers (83%) and that their volunteers were *always* on time (95%).

**In their Own Words: *Why I Became a Caregiver Respite Program Volunteer***

*It helps me stay strong and connected to others.*

*May need it in the future.*

*I was a Sr. Companion Volunteer and wanted to continue volunteering. I like to help people.*

*I arranged for respite volunteer training to be offered at my church. By participating in the training, I agreed to volunteer. I also was a long-distance caregiver for my Mom who passed away but I regretted that I could not have visited her on a more regular basis.*

*I felt the burden a person must have being responsible for a person 24 hours a day.*

*I am retired and able to give back to the community.*

*To help out by giving a caregiver a little time for themselves.*

*I have a passion to be an encouragement to those who are in need.*

*My husband died and I needed something to fill my life.*

Volunteers were involved in several different activities with care receivers and caregivers as shown in Table 7a and Table 7b. Most commonly they conducted friendly visits with care receivers (84% said they did this *frequently*, 95% *at least occasionally*), chatting or sitting together to watch TV (40% said they did this *frequently*, 70% *at least occasionally*). More than 60% of the volunteers also reported they share or prepare meals, or go on outings or walks at least *occasionally* (see also the appendix for specific responses from volunteers).

**Table 7a: What Did Volunteers Do for Care Receivers, at Least Occasionally?**

	ALL RESPONDENTS n=168
Friendly visiting/companionship	95%
Watch TV with him/her	70%
Share a meal or prepare food for him/her	65%
Go on outings	62%
Take him/her for a walk	60%
Provide transportation	48%
Play cards or other games with him/ her	32%

Caregivers confirmed volunteers' reports (see Appendix 3a), though they indicated that volunteers more frequently played cards or other games and less frequently prepared or shared meals. It was also clear from the responses that volunteers focused their efforts on interactions with care receivers, but as shown in Table 7b also frequently did tasks, especially listening, directly with/for caregivers.

**Table 7b: What Did Volunteers Do for Caregivers, at Least Occasionally?**

	ALL RESPONDENTS n=168
Provide listening/support	84%
Light housekeeping	28%
Run errands	20%
Minor home repair	6%
Yard work/snow removal	6%

Caregivers also confirmed volunteers' reports of tasks they do directly for them (see Appendix 3b). Fewer caregivers, however indicated that volunteers did light housekeeping, or spent time listening to them or providing direct support. As stated in prior reports, this is likely just a difference in awareness given the many demands on caregivers. Though the proportion of caregivers acknowledging frequent volunteer

listening/support was substantial, volunteers may still need to make sure caregivers know volunteers are available to help them too.

Through the survey, caregivers also reported how they spent their time while volunteers were visiting with care receivers. As shown in Table 8, most reported that they spend the time doing errands, relaxing on their own or shopping. Many also indicated they used the time to meet up with other friends or family members, or to take care of their own medical needs, although both volunteers and caregivers reported that caregivers often didn't leave the house while a volunteer was visiting. Many fewer caregivers indicated they used the time for working (33%, 2018 caregivers only) personal caretaking such as visiting the gym or the hairdresser/barber, or attending a class. Lifespan regularly offered Powerful Tools for Caregivers, a class for caregivers to help them manage their stress and enhance their personal situations. Those who did clearly benefited from learning caregiving tools and self-care (see page 22 and Appendix 4 for caregiver training results from classes conducted during Year 3 – 4 and detailed results for Year 5).

**Table 8: What Did Caregivers (n=82) Do When Volunteers Visited?**

	Occasionally	Frequently	TOTAL
Run Errands	31%	45%	76%
Just relax on own	38%	33%	71%
Grocery Shop	34%	36%	70%
Meet up with friends or family members	39%	22%	61%
Take care of their own medical appointments	31%	29%	60%
Work (2018 CGs only)	7%	26%	33%
Visit the hairdresser/barber or get a manicure or pedicure	19%	13%	32%
Attend a class or visit the library	16%	14%	30%
Visit the gym	14%	8%	22%

*Can't think of any negatives. Positives: I can't believe this class is free! Class size was perfect for sharing information and asking questions. The instructors were personable, friendly, prepared and skilled facilitators. Caregiver providing feedback about Powerful Tools for Caregivers, 2017-18*

## Respite Program Operations and Outcomes Through Year 5 (May 2018)

Review of program updates showed that the Caregiver Respite Program tracked and consistently achieved important program implementation requirements despite the challenging nature of the work and staff turnover at one of the partner agencies. The volunteer and caregiver surveys also provided opportunities for respondents to provide program assessments and report on family outcomes. These answers in particular highlighted the continued effectiveness of the Caregiver Respite Program across the five years of this study and illustrated the continued value to both caregivers and care receivers.

### *Program Operations*

As detailed in monthly reports, there was awareness of caregiver respite services available through Lifespan and Community Place. Community residents accessed NYConnects and other programs at Lifespan and Community Place as a strategy to learn about respite options. Multiple advertising, events and other outreach efforts took place. As described in section 1, volunteers learned about volunteer opportunities through multiple avenues including presentations by Lifespan staff, newspaper ads, friends/family and other volunteers and the Internet. Caregivers, were also exposed to multiple advertising and outreach efforts that took place across the five years.

- Through I & A, phone advisors served 4903 caregivers between June 1, 2014 and May 31, 2015; 5574 caregivers during 2015-16; 4879 caregivers during 2016-17; and 3392 caregivers between June 1, 2017 and May 31, 2018.
- Staff placed ads in the Pennysaver newspaper and on Rochester City buses for volunteers, conducted Outreach at Brighton Farm Market and spoke to Henrietta and Brockport Rotary groups. They also conducted outreach at Ibero for Hispanic caregivers and volunteers, at the Trinity Emanuel Church Fair – to reach an African American congregation, spoke on FOX Sports radio to recruit male volunteers, attended a Jewish War Vets lunch group and attended an Italian American Sports Club meeting. Additionally, staff participated in the RIT - Volunteer Fair, and the ABVI/Goodwill Volunteer Fair, met with members of other social organizations such as the Southwest Kiwanis group and met with Penfield Senior Center and conducted outreach at various senior housing locations. The partners developed the Refer-a-Friend initiative with existing volunteers to boost recruitment.

Continued independent review of data shows that for Lifespan increased numbers of volunteers were recruited and trained each of the five years and that most who initiated the process stayed with it and provided respite even though it was very demanding. The data also show that as volunteers retired after services, new volunteers took their places to meet demand. Note also that in 2016-17 Lifespan upgraded

its data systems and added staff to the Caregiver Respite Program team to help streamline the complex processes of volunteer vetting, assessment and matching. By Year 5 this led to substantially shorter placement timing and led to multiple long-term matches (e.g., average placement time in Year 1 was 84 days, but only 46 days in Year 5, see Appendix 2 for details). Community Place recruitment was about the same Year 1 and year 2 but fewer volunteers were recruited for Year 3 and then recruitment increased again for Year 4. During Year 5, many volunteers, caregivers and care receivers continued their relationships, new recruits from Year 4 were placed and 3 new volunteers were recruited.<sup>9</sup> Respite activity continued. Across the 5 years, both Community Place and Lifespan provided regular training for volunteers (and caregivers at Lifespan). Additionally, since Year 2, both organizations have worked to track and communicate with volunteers and caregivers and to assess caregiver needs. Both programs also supported evaluation requests, continued to keep stakeholders informed and addressed ongoing fund development needs. Continuing from Year 4, the program has maintained its institutionalized status at both organizations (see note <sup>8</sup>) and it was effectively replicated by other Lifespan staff as part of the Finger Lakes Caregiver Institute (starting spring 2017 and continuing thereafter).

### ***Program Outcomes***

Table 9 shows volunteer and caregiver assessments of Caregiver Respite services. It can be seen in the table that almost all volunteers (87%) and caregivers (88%) rated the program as *useful* or *very useful*. It can also be seen that a substantial majority of volunteers thought their matches with both caregivers and care receivers were *good*. This was confirmed by caregivers.

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<sup>9</sup> Community Place experienced staff turnover that limited consistent program documentation for some of 2017-18. However, assessments were made, volunteers were placed, existing cases were sustained and multiple volunteer hours were provided despite organizational shifts. By the end of Year 5, staff roles were re-solidified.

**Table 9: Volunteer and Caregiver Assessment of Caregiver Respite Service**

% who . . .		
	VOLUNTEER n=168	CAREGIVER n=82
Rated caregiver respite <i>Useful/Very Useful</i>	87%	88%
Thought Match with Care Receiver was <i>Good*</i>	85%	91%
Thought match with Caregiver was <i>Good*</i>	78%	88%

\* A total of 168 surveys were answered by the 143 volunteers as many of them had more than one volunteer experience over the five years of the initiative. Items identified with an \* above are questions that were asked in reference to a particular volunteer experience.

Note also that limited caregiver data (n=9) were obtained for Community Place.

The partners spent a considerable amount of time identifying volunteers that could work well with specific caregivers/care receivers. These efforts were consistent across the five years. The responses shown above, and many of the direct comments confirm the value of volunteer respite efforts.

#### **Caregiver/Care Receiver/ Volunteer Relationships are Unique**

*The husband [caregiver] was isolated, stressed, tired. I listened and gave occasional suggestions. For example, she would get up during the night, take all of her numerous shoes out of the boxes and scatter. I suggested hiding most of them. Volunteer, 2017-18*

*The caregiver does not live with his mother. I talk to him on the phone and often we communicate via text. There have been a few times he has come to the house and we talk briefly.*

*When no one else is visiting and it's just she and I, my visits last about 3 hours. We might take a walk, or I might help her complete a task, I often help fix a snack and encourage her to take her pills, we talk a lot and laugh a lot. I do enjoy my time spent with her and she's told me she enjoys my visits. All winter, she often said she didn't want me to leave and I hated leaving her alone. She's busier now with ElderOne, an aide and her male friend. Volunteer, 2017-18*

*He is always relaxed in my presence but if not, I get him to the point where he is relaxed and can enjoy the time we spend together. Volunteer, 2017-18*

*My visits allow the caregiver time to exercise and I can tell the care receiver appreciates the one-on-one undivided attention I can give him. Volunteer, 2017-18*

In addition to support for volunteers (e.g., recruitment, training, matching), since 2015-16, Lifespan has also provided and assessed *Powerful Tools for Caregivers (Powerful Tools)* training. Response to and documented assessment of the program by participants was very positive (see Appendix 5). Specifically:

- Across Year 3 (n=10), Year 4 (n=23) and Year 5 (n=102), all or almost all participants rated each week of the program, the leaders and the program overall as *Good* or *Excellent*.
- All responding participants in all three years indicated that as a result of the class they believe *they are more confident caregivers than before taking the class*.

For Year 5, substantial numbers of participants participated in *Powerful Tools* and also completed pre- and post-program assessments. Those results confirmed increased preparedness related to caregiving rolls (see, Appendix 4a, 4b, and Appendix Figure 4c). For example:

- Across Year 3 (n=10), Year 4 (n=23) and Year 5 (n=102), all or almost all participants reported they were *at least somewhat* prepared to use powerful caregiver skills.
- In Year 5, for the 52 respondents who completed both pre- and post-assessments, there were quite substantial changes in the percentage of respondents who indicated they were prepared for caregiving. For example:
  - On the pre-survey 20% of respondents indicated they were at least *pretty well* prepared to handle caregiving overall. This was true for 92% of those same respondents on the post-survey (a 72 percentage point increase).
  - On the pre-survey only 14% of respondents indicated they were at least *pretty well* prepared to create a personal action plan for caregiving. This was true for 83% of those same respondents on the post-survey (a 69 percentage point increase).

### ***Family Outcomes***

Tables 10 and 11 provide final summary measures regarding family outcomes. It can be seen in Table 10 and Figure 1a that **almost all volunteers and caregivers rated caregiver respite as *somewhat* or *very helpful* for both caregivers and care receivers**. Specifically: a total of 98% of volunteers and all caregivers rated the program as *somewhat helpful/very helpful* for caregivers; a total of 98% of volunteers and 99% of caregivers rated the program as *somewhat helpful/very helpful* for care receivers. On the 2017 and 2018 caregiver surveys, respondents were also asked whether the respite program was helpful to caregiver companions and 75% of respondents, who had companions indicated caregiver respite was *somewhat helpful/very helpful*.

**Table 10: Helpfulness of Caregiver Respite Service According to Volunteers and Caregivers**

% who . . .	%	
	VOLUNTEER n=168	CAREGIVER n=82
Rated caregiver respite <i>Somewhat Helpful/Very Helpful</i> to the <b>CAREGIVER</b>	98%	100%
Rated caregiver respite <i>Somewhat Helpful/Very Helpful</i> to the <b>CARE RECEIVER</b>	98%	99%

\*Note the survey asked volunteers to rate helpfulness for each case they have been involved in. A total of 168 surveys were answered by the 143 volunteers as many of them had more than one volunteer experience. Answer choices included: *Not at all helpful, Somewhat helpful, Very helpful.*

It can be seen in Table 11 and Figure 1b that **almost all volunteers (96%) reported that they had helped to reduce caregiver stress.** A number of volunteers however, indicated they had only helped to reduce stress *somewhat* for caregivers. **Caregivers themselves were more definite about stress reduction: 96% of them indicated the Caregiver Respite Program helped them reduce stress (only 12% said *somewhat*).** Table 11 also shows that **both volunteers and caregivers thought the Caregiver Respite Program helped improve the quality of life for the care receiver.** Again, some volunteers indicated they had only improved the care receivers' quality of life *somewhat*. **Caregivers were also more definite about the quality of life improvements: 96% of Caregivers indicated the Care Giver Respite program helped improve the quality of life for their family member.**

**Table 11: Caregiver and Care Receiver Outcomes, According to Caregivers and Volunteers**

% who reported that . . .	2014-15 – 2017-18	
	VOLUNTEER n=168	CAREGIVER n=82
Caregiver Respite Program helped <b>reduce Caregiver's stress</b>	96%	96%
Caregiver Respite Program helped improve quality of life for the <b>care receiver</b>	94%	96%

\*Note the survey asked volunteers to rate helpfulness for each case they have been involved in. A total of 168 surveys were answered by the 143 volunteers as many of them had more than one volunteer experience. Answer choices included: *No, Somewhat, and Yes for each question.*

Figure 1a: Helpfulness of the Caregiver Respite Program

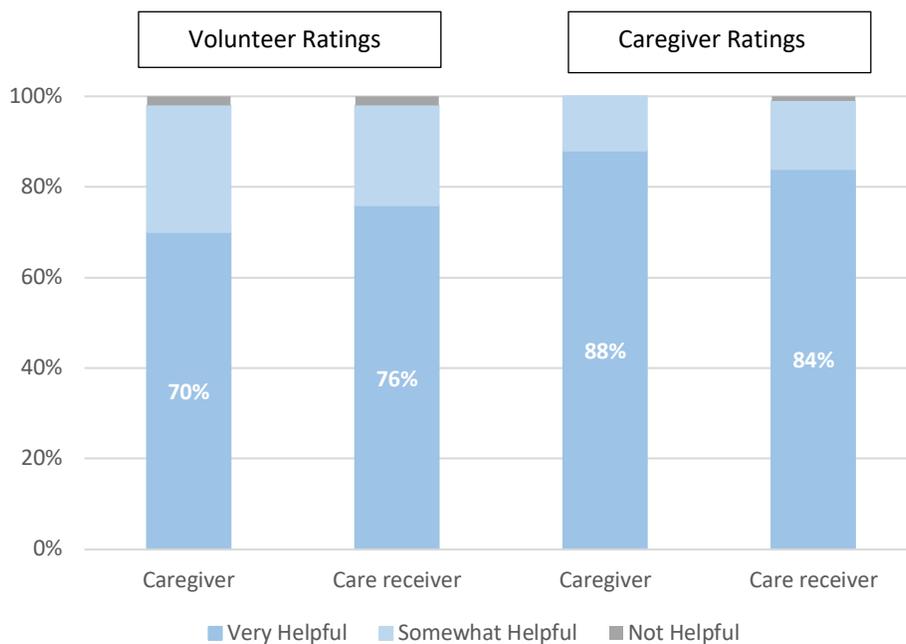
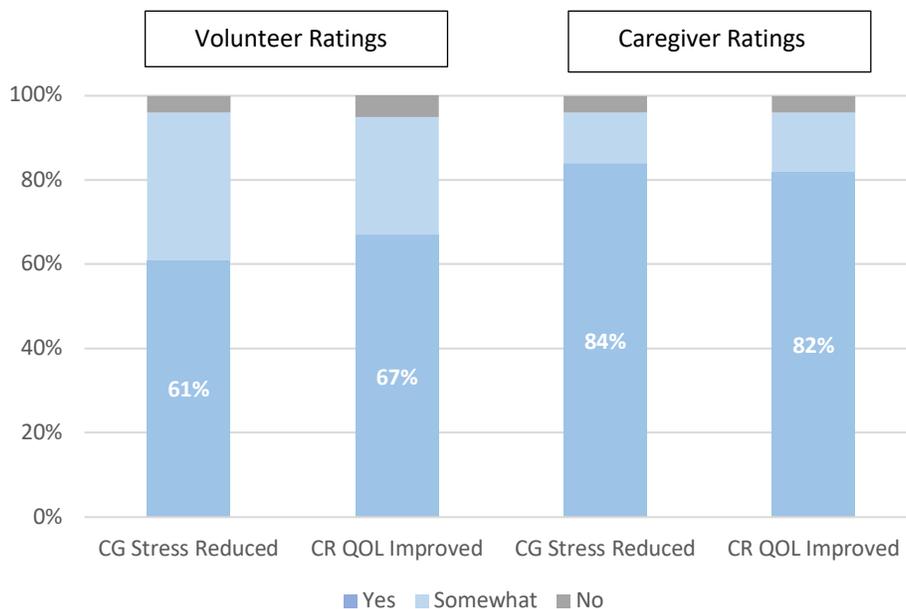


Figure 1b: Ratings of Caregiver Stress Reduction and Care Receiver Quality of Life Improvement



### III. CONCLUSIONS AND ISSUES FOR FURTHER CONSIDERATION

As described in the previous sections, the Caregiver Respite Program has become institutionalized and through the partnership is reliably able to produce promised outcomes despite the considerably complex and challenging nature of the work. As the program has reached long-term duration, which adds to its value to clients, program staff have had to take on additional requirements to continue balancing maintenance of relationships with recruiting, training, record-keeping, and re-assignment for an ever-growing and changing population. Additionally, the program at Lifespan has added additional collaborative channels as Caregiver Respite Program staff interact with Lifespan's Finger Lakes Caregiver Initiative (FLCI) staff and have taken on Project Hope with the University of Rochester. Throughout the five years, the program has continued to use established collaborative practices, delivered on its objectives to recruit, screen, train and match volunteers with caregivers/care receivers, and to support their ongoing efforts while promoting reduced stress for caregivers and maintaining/enhancing quality of life for care receivers. Using similar but customized, complex strategies including care receiver assessment and volunteer/caregiver matching, the partners have continued to address a critical community need and to inform replication of volunteer respite strategies through other initiatives. Though recruitment and oversight for the program are always demanding for both partners, the number of trained and capable volunteers has consistently met or exceeded targeted levels, new volunteers have been recruited each year, substantial outreach to caregivers has occurred and new viable matches were made while existing matches and volunteers continued to be supported for multiple years in many cases. Additionally, substantial levels of service have been delivered, the program continued to grow, and feedback from volunteers and caregivers has been overwhelmingly and very consistently positive. Specific findings include the following.

- **Through all five years, volunteers ensured that respite happened, and the Lifespan and Community Place partners ensured that volunteers were recruited, cleared, trained and supported** as they provided services. Over the five-year period the partners worked with more than 244 potential volunteers. This included both male and female volunteers and those who came from the city and the neighboring towns. About 11% of the volunteers were African American, 7% were Hispanic/Latino, 81% were Caucasian. Most active volunteers were in their 60s and 70s (the average age overall was 66).
- **The program continued to grow.** Due to both continued recruitment and longevity of matches there was a 21% increase in the number of volunteers involved (Year 5 compared to Year 4), and there were many more active matches in Year 5 (+20%

- **Caregiver needs were diverse.** Many of the caregivers were contemporaneous with the volunteers (in their 60s and 70s), but some were younger and some were older, including several who were 90 or older. More than 70% of the caregivers were female, many caring for a spouse or an aging parent, and many had additional family members such as adult children who also helped with caregiving responsibilities (and required additional respite care attention).
- **During Year 4 and Year 5, Lifespan began to collect additional data about companion caregivers.** A total of 40 caregivers, usually spouses, have additional family-based assistance, mostly grown children. They are involved and supportive, but most decisions rest with the primary caregivers (often informed by the care receiver).
- **Care receivers had multiple needs.** The care receivers were older (many were in their 80s or 90s). Slightly more than half (58%) were female and most (76%) lived with their spouses or other family members. In addition to care receivers with Alzheimer’s (including early onset Alzheimer’s), there were care receivers with Lewey Body dementia, FT dementia and other early dementia-related challenges such as confusion and memory loss. Though most were mobile, they were medically frail in addition to their dementia. In longer-running matches, the challenge of visiting with increasingly diminished care receivers can become increasingly difficult as illustrated by the following comments.
- **Caregiver Respite Program staff continue to use effective strategies for accomplishing widespread respite. Recruitment is ongoing and staff continued to conduct assessments and offered scheduled training, while also providing additional supports when needed and new matches for cases that discontinued.** Overall across the five years, more than 50,841 hours of respite were provided. A total of 336 families and 207 volunteers accessed the Caregiver Respite Program.

*[I need more training on] how to deal with people who are unable to communicate with others. [The caregiver] is challenged with her care receiver not being able to talk/communicate with her or her family. Volunteer, 2017-18*

*I may need more training if my caregiver’s situation changes. Volunteer, 2017-18*

*She doesn't like to go any place (paranoia). I keep trying with her. She went one time. Volunteer, 2017-18*

- **Many successful matches were made and sustained with volunteers and caregivers from both partner agencies.**
  - More than 244 potential volunteers accessed the Caregiver Respite Program, 207 of those prepared for or provided respite, including 170 who served. This included: 98 available volunteers at the end of Year 5, 19 others on-hold (who have not officially retired, but did not provide respite in 2017-18), and 3 who were in-process, 26 volunteers who completed all training but then decided to pursue other callings, and 61 volunteers who had retired after service.

- Almost all of the 336 caregivers who accessed Caregiver Respite Program were assessed, and in most cases (76%) matched with a volunteer (an additional 4% were waiting for a first match at the end of Year 5).
  - Half (50%) of the Lifespan volunteers with cases opened by 5/31/2017 had matches that lasted one-year or longer, several extended more than two years. There continued to be new matches each year of the program.
- **The Caregiver Respite Program retained many volunteers – one-third of Lifespan’s volunteers have been with the program since the first or second year, 80% have been with the program more than a year. The partners clearly continued to manage re-assignment so that training and long-term effort were maximized to sustain respite options.** Many phone calls were made to volunteers, potential volunteers, caregivers, and caregiver companions to keep the process operational. Additionally, regular meetings were conducted with volunteers to provide continued training and support. Volunteers reported via the survey that they felt supported and their training was sufficient. Increasing numbers of volunteers continued to take on matches after closing a match and multiple volunteers had more than one open match.
  - **Through Year 4, available data showed that matches closed mostly due to changes in the care receivers’ conditions.** This along with new challenges and changes in circumstances (e.g., health issues, moving), for the volunteer population were confirmed by staff as primary reasons for matches closing during Year 5.
  - **Feedback from volunteers about their volunteer experience was consistently very positive.** Almost all volunteers rated their volunteer experience as *meaningful/very meaningful* and agreed they were *satisfied/very satisfied* with their experience. Despite many having now served multiple years, all but a few respondents reported they would continue volunteering and would recommend Lifespan or Community Place to others.
  - **Volunteers were involved in several different activities with care receivers and caregivers.** Most commonly they conducted friendly visits with care receivers, chatting or sitting together to watch TV. Almost two-thirds of the volunteers also reported they shared or prepared meals, or went on outings or walks at least *occasionally*. Caregivers confirmed volunteers’ reports. **It was also clear from the responses that volunteers focused their efforts on interactions with care receivers, but also frequently did tasks, especially listening, directly with/for caregivers.**
  - **Caregivers used their respite time, mostly to take care of family needs and to take some breaks.** Most reported that they spent the time doing errands or shopping. Many also indicated they used the time to just relax on their own, to take care of their own medical issues, or to meet up with family or friends. Many fewer caregivers indicated they used the time for personal caretaking such as visiting the gym or attending a class.
  - **Lifespan regularly offered the Powerful Tools for Caregivers class to help caregivers manage their stress and enhance their personal situations. Positive feedback about the classes and substantial increases in skill development were reported.**

- There was continued awareness of caregiver respite services available through Lifespan and Community Place and community residents are accessing NY Connects as a strategy to learn about respite options. Each year, multiple advertising and outreach efforts were conducted.
- Across all five years, feedback from volunteers and caregivers about program and family outcomes has been very consistently positive. For 2017-18:
  - Almost all volunteers (87%) and most caregivers (88%) rated the program as *useful* or *very useful*.
  - More than three-fourths of volunteers thought their matches with both caregivers and care receivers were *good*. This was confirmed by caregivers. Some matches are better than others and there remain challenges such as scheduling and caregiver/ care receiver willingness to participate
  - Almost all volunteers (98%) and all of their associated caregivers (100%) rated caregiver respite as *somewhat* or *very helpful* for both caregivers and care receivers (most rated Caregiver Respite Program as *very helpful*).
  - Almost all volunteers (96%) reported that they had helped to reduce caregiver stress at least *somewhat* and caregivers (96%) confirmed volunteers' reports.
  - Both volunteers (94%) and caregivers (96%) thought the Caregiver Respite Program helped improve the quality of life for the care receiver.

### **Issues for Further Consideration**

1. *Maintain the existing program and the many sustainable strategies that were developed to support caregiver respite. Continue to support effective collaboration between partner organizations. Continue to focus on productive volunteer recruitment strategies including ongoing support and evaluation of Project Hope. Many volunteers have multiple years of service and will continue to phase out of their efforts as the many retired volunteers have done.*
2. *Continue program support especially for the matching process and working to rapidly place volunteers and maintain matches. Make sure all caregiver and volunteer requests for information or support are addressed as quickly as possible. Continue informing replication efforts.*
3. *Continue working to ensure as many trained volunteers as possible are actively providing respite services. Provide extra support to those in very new or those in longer-term matches as needed. Continue to do whatever is needed to support and sustain existing matches. Make sure volunteers have continued support, possibly by learning from other volunteers, to help them work effectively with care receivers.*
4. *Continue to focus on outreach, recruitment and retention of volunteers, and outreach to caregivers to participate in caregiver training. Powerful Tools for Caregivers training results show very promising results. Continued study of what is needed to increase participation is strongly advised.*
5. *Be sure to continue to factor in the need for volunteers to take time off between difficult matches, but to stay connected so they return to provide respite for multiple cases. Investigate whether volunteers "On-Hold" can be returned to active service, re-assign matches where needed and track match status fully.*
6. *Review again whether current staffing levels at each agency are sufficient to manage the volume of project operations.*
7. *Continued attention to complete and accurate record keeping is advised. Both partner organizations are encouraged to continue reviewing coding and data management regularly, and to ensure that Community Place data is fully restored going forward.*

## Other Volunteer and Caregiver Quotes

*M. is the best volunteer we have had. We have socialized with she and her husband on one occasion. She seems more like a friend. I so appreciate her volunteering to do this!* **Caregiver Respite Caregiver, 2018**

*I help [the Care Receiver] assist in making greeting cards and writing notes* **Caregiver Respite Program Volunteer, 2018**

*We went to Mass together at the facility and went to Women's Group together for pizza and games at the facility.* **Caregiver Respite Program Volunteer, 2018**

*We are all comfortable and consider each other friends.* **Caregiver Respite Program Volunteer, 2018**

*She has support to keep care receiver safe, fed, etc but to be a companion and take out, no.* **Caregiver Respite Program Volunteer, 2018**

*I think for the few hours I am visiting with her, maybe he feels relief knowing she's not alone for those few hours. But I think his stress comes more from the fact that she lives alone. A month or so ago, her stove was turned off and now she has a hotpot to heat water for tea. She does use a microwave, but I think there are safety issues because she lives alone that likely cause him the most stress.* **Caregiver Respite Program Volunteer, 2018**

*I have little contact with them although one son does know I visit and has said they could use more people like me. I know he is glad that I do the things with his Mom that I do.* **Caregiver Respite Program Volunteer, 2018**

*He is always relaxed in my presence but if not, I get him the point where he is relaxed and can enjoy the time we spend together.* **Caregiver Respite Program Volunteer, 2018**

*I have had only one person so far, but it was a very good experience. I am looking forward to having another client someday.* **Caregiver Respite Program Volunteer, 2018**

*I think that my connection with the family has made a big difference with both the family and myself.* **Caregiver Respite Program Volunteer, 2018**

*I know the caregiver is very appreciative of the time I spend with her husband and I am happy for that. Also, I have enjoyed the time spent and conversations I have had with both of them.* **Caregiver Respite Program Volunteer, 2017**

*For the time that I am with the care receiver he is vibrant, enthused, excited, verbal and ready to go. He is very friendly and is excited when we work together on different activities.* **Caregiver Respite Program Volunteer, 2017**

*I wanted to help someone and I get great pleasure from that.* **Caregiver Respite Program Volunteer, 2017**

*[Our volunteer] is a gem. Very loving, caring, respectful, always polite, very kind.* **Caregiver Respite Program Caregiver, 2017**

*Thank you for this program, Mom has thrived with the attention she is getting from her volunteer. And it is nice to get a break and feel that Mom is safe.* **Caregiver Respite Caregiver, 2017**

*I feel that the care receiver [B.] that I see is very grateful for my visits. It is a unique situation, I think because [she] is in her own independent apartment. She has dementia, early stages but she has little memory to rely on. I have little contact with the family. I can communicate with one of her sons by email which I do. I usually tell him when I've been there and what we do. He is thankful for the time I spend with his Mom. It happens sometimes that when I go, the family shows up or has taken [B.] out and then it is a wasted trip. There is little reason to call her before because she often doesn't know if there is something planned.* **Caregiver Respite Program Volunteer, 2017**

*Because I don't talk much with family, I just create or come up with something to do each time I go. So, it takes a bit of imagination to figure out something to do [B.] has no suggestions. She likes to watch baseball on TV and knit. I often need to explain why I am there but she does recognize me as a familiar face and I always give her a big hug when I leave. I know she loves the hug and she says I am so nice and it was such a fun visit and thanks me. I know she and her family appreciate the visits.* **Caregiver Respite Program Volunteer, 2017**

*I had cared for my Mom and after she passed away, I wanted to provide some respite to another caregiver, knowing how much time it takes and the emotions the caregiver must deal with.* **Caregiver Respite Program Volunteer, 2017**

*I meet with Bob weekly. When the weather is nice, we hang out with my two grandsons, ages 4 and 2. They know him as "Grampa Bob" and he always asks about them. Other times, Bob and I go "garage sale-ing" on Fridays. Bob reminds me of my father, who I loved dearly.* **Caregiver Respite Program Volunteer, 2017**

*I continue to enjoy my time spent with G. We cover a great deal of territory in our conversations."* **Caregiver Respite Program Volunteer, 2017**

*We had several good conversations and looked at family pictures. She is very sweet and appreciative of my visits. We are looking forward to our next visit.* **Caregiver Respite Program Volunteer, 2017**

*I couldn't ask for anything more than the friendship my Mom, husband and I shared with our caregiver.* **Caregiver Respite Program Caregiver, 2017**

*More time in the day. Every day is the same stress wise. Support - what really helps is knowing the volunteer is there.* **Caregiver Respite Program Caregiver, 2017**

*The fact that [my volunteer] has experience with Alzheimers/dementia provides confidence to me in leaving her in his care so that I can accomplish the needs for my husband and myself.* **Caregiver Respite Program Caregiver, 2017**

*Someone 24/7 !!! Only kidding, but more than once a week would be great. HOWEVER, I'm counting my blessings he is here voluntarily each week. What a great service to provide.* **Caregiver Respite Program Caregiver, 2017**

*I enjoy visiting with him, he is a very interesting person and we have many laughs. We enjoy each other's company and joke about weather and politics. Our talking has been helpful as I am told by his family. We have developed a wonderful friendship.* **Caregiver Respite Program Volunteer, 2017**

*I had hoped to have more of a connection and be able to do more fun things with my care receiver. When I listened to the other volunteers tell their stories of visits with their care receiver, it certainly seemed as though they were more active and had a more interactive relationship.* **Caregiver Respite Program Volunteer, 2017**

*Very early I asked him if he'd like to go out for a ride and he said he would. We did it perhaps three times. Once we went out for lunch. Ever since he hasn't wanted to go out. We put together jigsaw puzzles every time we meet. He enjoys that.* **Caregiver Respite Program Volunteer, 2017**

*For the time that I am with the care receiver he is vibrant, enthused, excited, verbal and ready to go. He is very friendly and is excited when we work together on different activities.*

**Caregiver Respite Program Volunteer, 2017**

*I listened and had conversations with the caregiver, which I believe was appreciated, though I felt as though she needed more help than I was giving.* **Caregiver Respite Program Volunteer, 2017**

*The care receiver is still very skeptical and doesn't want her care giver to leave her sight. It's getting a bit better and he has managed to leave for 45-60min during the last few visits.* **Caregiver Respite Program Volunteer, 2017**

*The program was very helpful for M.R. and the family - relieving the stress that one carries when at work and their home.* **Caregiver Respite Program Caregiver, 2017**

*It has been such a blessing. Even visited in hospital. Can't say enough about the program.* **Caregiver Respite Program Caregiver, 2017**

*My wife didn't like the volunteer but she would not have liked anyone that volunteered.* **Caregiver Respite Program Caregiver, 2017**

*The lady I work with is very nice. Just her busy schedule and mine have not seemed to work out yet. As wife's dementia progresses respite care will become more important !!!* **Caregiver Respite Program Caregiver, 2017**

*Thank you for this program, Mom has thrived with the attention she is getting from her volunteer. And it is nice to get a break and feel that mom is safe.* **Caregiver Respite Program Caregiver, 2017**

*I have loved being involved with and getting to know the woman to whom I have been assigned as a Caregiver Respite Volunteer. At the beginning my time with her was quite difficult, but thankfully I persevered and we now have a nice friendship - meaningful to both of us!* **Caregiver Respite Program Volunteer, 2016**

*My B. has touched my heart. We are friends as if we have been for years. She is so appreciative of my visits, I wish I had more time.* **Caregiver Respite Program Volunteer, 2015**

*Helping others makes me feel good about myself, it is very rewarding.* **Caregiver Respite Program Volunteer, 2015**

*I became a volunteer to meet new people. I've stayed a volunteer so I can be there for Laurel. Caregiver Respite Program, 2016*

*[The volunteer] was about the only outside person who visited my mom before she died. Respite Care Caregiver, 2015*

*I read on the 101 things to do Sheet - **dance**. While R. was listening to music, I asked her to dance once. Now she initiates it. There are not many things she can do on the sheet. We have painted, played badminton, cut flowers for a bouquet. While she is often not very verbal, she does make more comments as we spend more time together. Volunteer, 2015*

*I love helping people and this program helps people who can't afford to have [a home health aid] or other agency. Volunteer, 2015*

*I bring my lunch and we eat together. She loves having company at her table. She smiles more. I joke with her and make her laugh. She sleeps less. Volunteer, 2015*

*This work is meaningful to me because I know that the caregiver uses this time for his favorite activity. I am becoming part of a family in crisis. I value the woman I care for. Volunteer, 2015*

*I wish I could have come more often. Two hours is short for a week's worth of waiting. Volunteer, 2015*

*I remind her to eat. Volunteer, 2015*

*I was a fresh face and we had a good time together. I was not burdened or tired of her because I saw her for such a short time. Volunteer, 2015*

*Initially I decided to volunteer because I was asked to do it and I had some spare time. Now it is because I really like it. Volunteer, 2015*

*I have been assigned to two cases so far and I believe that I have made a difference for both patients and their caregivers. Volunteer, 2015*

*This work is meaningful to me because I know that the caregiver uses this time for his favorite activity. I am becoming part of a family in crisis. I value the woman I care for. Volunteer, 2015*

### **Caregiver and Volunteer Suggestions**

*Quicker response to requests. It took ten months to get a volunteer! Caregiver 2018*

*Making more free respite time available. Caregiver 2018*

*Should I do more with caregiver? Volunteer 2018*

*More meetings to know more volunteers. Volunteer 2018*

*It would be nice to hear feedback if they contact the family to ask how I am doing. Volunteer 2018*

*I think it would be even more meaningful if there was more connection with my caregiver's family. But I feel a little like it is visiting in our own little bubble. **Volunteer 2018***

*How to deal with people who are unable to communicate with others. She is challenged with her care receiver not being able to talk/communicate with her or her family. **Volunteer 2018***

*I enjoyed the gathering of Lifespan people and volunteers that I attended last winter. I missed the most recent get together. Maybe have a few more? It's nice to hear others' talk about their experiences. Sharing is always helpful. **Volunteer 2018***

*Streamline the application process--from the day I called initially until a caregiver from the specified agency was in my home was 10 weeks. I also think that inquiry needs to be made during the application process regarding other agencies in the home for the affected person and how there can be coordination of the same agency for the respite services. **Caregiver 2017***

*Provide some practical advice to use during visits or when issues come up, for example, what to do when the care receiver does not want to do anything you suggest, how to deal with the care receiver calling me for assistance. **Volunteer 2017***

*Possible short midyear meeting with other respite care givers to brainstorm ideas for care receiver activities. **Volunteer 2017***

*I feel some more training to deal with specific circumstances or possibly some role-playing may have helped. While the Alzheimer's training was educational, I feel some more practical approaches to visits would have helped. **Volunteer 2017***

*We could use more frequent visits, but it has been a big blessing. These are thoughtfully planned visits. **Caregiver 2015***

*I sometimes have difficulty on the first try for contact with the staff. The recording always says they are away from their desk or on another line. In all fairness I do get a call back but sometimes I'm not there. **Volunteer 2016.***

*The information sheet was very helpful. **Volunteer 2016***

*More contact with Lifespan might have benefitted the caregiver because I might have been able to offer her more resources or information by keeping Lifespan informed on her situation. **Volunteer 2016***

*Maybe some follow-up 1 – 2 weeks after initial assignment. **Volunteer 2015***

*He aprendido muchas rosas que creia saben y realmente no era como yo pensaba. I have learned many things that I thought I knew but really they weren't what I thought they were. **Volunteer 2015***

*It would be awesome to come often and be able to take her out. **Caregiver 2016***

*Groups of volunteers that could take a group of them out together, i.e.: zoo, etc. Entertaining for everyone; small group with volunteers and care receivers. **Caregiver 2016***

*Communication of the program needs to be out in community- purpose, cost, etc. Ran into a posting somewhere by accident.*

*Match sooner- it took a very long time for the match to take place. **Caregiver 2015***

*More time available to spend with care receiver 2) need longer term visit for overnight or vacation **Caregiver 2016***

*We would love some coverage for vacations. Would like more services- another caregiver when volunteer can't be there. **Caregiver 2016***

*We need someone who could come on a more regular basis- We worked around her schedule. **Caregiver 2017***

## Baker Appendix 1: Program Partners and Overview

**Lifespan.** As stated in their promotional materials, Lifespan’s sole mission is to help older adults take on both the challenges and opportunities of longer life. Lifespan provides a continuum of direct services and unbiased information, guidance and advocacy for older adults and caregivers. It also provides training and education for allied professionals and volunteers. Lifespan also operates both the New York State Caregiving and Respite Coalition and the Monroe County Caregiver Resource Center and it serves as the lead agency in the Caregiver Respite Program. Lifespan initially utilized its existing *Partners in Caring* volunteer-based companion program as a strategy for recruiting volunteers and providing respite services to the identified target population. The Caregiver Respite Program uses volunteers to provide friendly visiting to older adults and respite for their caregivers. Volunteers receive mileage reimbursement and average about four hours of service per week. The program is overseen by the Lifespan Manager of Education and Caregiver Services. Throughout the five-year period, the team consisted of the coordinator of the Caregiver Resource Center, the Partners in Caring Care Manager, and an administrative assistant. For Year 5, the team added a full-time Care Manager and added a Volunteer Coordinator. The team managed recruitment, screening, training, matching and general oversight for all volunteer/caregiver-care receiver matches.

**Community Place of Greater Rochester.** Community Place is a nonprofit that utilizes collaborative partnerships in order to ensure the delivery of cost-effective, high-quality developmental and social programs and services in the areas of Aging Services, Youth Development, Family Services, Early Childhood, and Developmental Disabilities. Community Place utilized its *Senior Companion* program as a strategy for recruiting volunteers and providing respite services to the identified target population. Senior Companions receive a small stipend of \$2.65 per hour and mileage reimbursement. The Senior Companion typically provides 20 hours of service per week. The program was overseen by the Director of Aging Services and an SCP Respite Coordinator throughout Years 3 through 5: multiple individuals have held those positions. Community Place staff provided screening, training, matching and general oversight for their Caregiver Respite Program volunteers.

Screening	Training	Matching and Support
<p>Both Lifespan and Community Place perform a thorough orientation and screening process:</p> <ul style="list-style-type: none"> <li>• Interview</li> <li>• Criminal background check</li> <li>• DMV check</li> <li>• Reference checks</li> </ul>	<p>Training is handled in a two-step process.</p> <ol style="list-style-type: none"> <li>1. Aging process – dementia, using Alzheimer’s Association training modules: Understanding Alzheimer’s, Managing Behavior related to Alzheimer’s, Communication. Uses case studies and scenarios and includes follow-up sessions.</li> <li>2. Expectations/Logistics including responsibilities. communication, confidentiality, boundary setting and activity tips.</li> </ol>	<p>Volunteers are invited to quarterly lunch &amp; learn meetings at Lifespan. Community Place volunteers attend mandatory monthly in-service training.</p> <p>Using the geriatric assessment, caregiver/care receivers are carefully matched to facilitate service effectiveness and longevity.</p>

# CAREGIVER RESPITE PROGRAM OVERVIEW

One Phone Number

NYConnects 325-2800 for information, options and connection to respite services



Phone assessment and triage.

- Need/desire for respite
- Eligibility for programs
- Determination if need a



Referral made to Programs at Lifespan and Community Place. Staff schedules an in-home assessment. All caregivers are informed about Powerful Tools for Caregivers



If appropriate respite program, Care Managers discuss options.

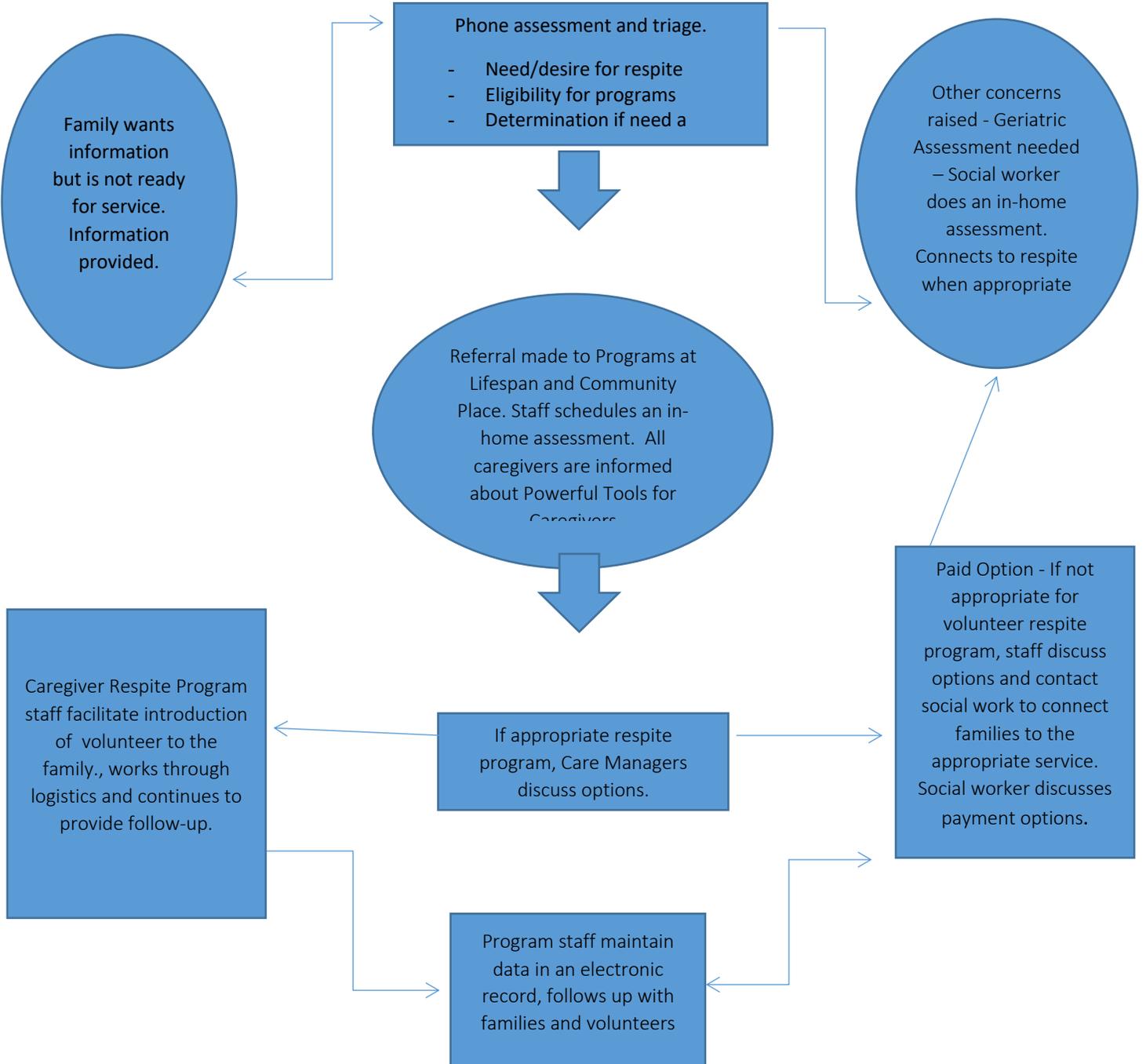
Paid Option - If not appropriate for volunteer respite program, staff discuss options and contact social work to connect families to the appropriate service. Social worker discusses payment options.

Caregiver Respite Program staff facilitate introduction of volunteer to the family., works through logistics and continues to provide follow-up.

Program staff maintain data in an electronic record, follows up with families and volunteers

Family wants information but is not ready for service. Information provided.

Other concerns raised - Geriatric Assessment needed – Social worker does an in-home assessment. Connects to respite when appropriate



## Baker Appendix 2: Match Status Details 2013-14 through 2017-18, Lifespan Volunteers

Across the five years, Lifespan worked extensively with a total of 159 volunteers. This included 53 who had active matches as of May 31, 2018, 18 who were waiting for a new match and 4 who were waiting for a first match, 44 who had resigned after service, 11 whose respite efforts were on-hold due to their own health challenges or changes in circumstances (e.g., moving), and 26 who elected to pursue other interests after completing all training. Across the five years, 126 Lifespan volunteers provided respite for multiple caregivers.

- As of 5/31/18, a total of 73 volunteers had active matches, including 3 volunteers who had more than 1 active match.
- A total of 23 volunteers had both active and closed cases including 9 volunteers who had an active case as of 5/31/18 but had already served 2 or more cases that closed, and several other combinations of active and closed cases.
- A total of 105 volunteers who had worked with at least 1 case that was closed as of 5/31/18 (34 of whom had 2 or more closed cases).

Most of the 126 volunteers that had had an active match, provided respite for one family but 46 had done so for two or more families and one had worked with 5 families, one with 6. A total of 200 matches have been undertaken across the five years. **During Year 5, time before the first match was substantially reduced (half as much as in prior years), and in both year 4 and 5 the match range was substantially reduced as well.**<sup>10</sup> Caregiver Respite program staff have streamlined their process so that trained volunteers can begin providing respite sooner.

- In 2013-14, the amount of time between training and first match ranged from 0 – 1220 days; average was 84 days.
- In 2014-15, the amount of time between training and first match ranged from 7 – 527 days; average was 76 days.
- In 2015-16 the amount of time between training and first match ranged from 6 – 482 days; average was 136 days.
- In 2016-17, the amount of time between training and first match ranged from 14 – 267 days; average was 72 days.
- In 2017-18, the amount of time between training and first match ranged from 0 – 211 days; average was 46 days.

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<sup>10</sup> Note that match ranges were affected by outliers – volunteers who had very specific circumstances, or required a time-out after training but before matching occurred. This was much less prevalent during Year 5.

### Baker Appendix 3: Caregiver/Care Receiver Case Status Framework

For evaluation purposes, all caregiver/care receiver requests were reviewed and status<sup>11</sup> as of 5/31/18 was recorded according to the following framework.

MATCH STATUS	CR = Care Receiver CG = Caregiver
DIVERTED*	CG requests assistance, but CR not appropriate for LS
ACTIVE/MATCHED	Volunteer visited CG/CR at any time April 2013 – May 2018
IN PROCESS	
Waiting for First Match	Volunteer trained, matching and/or visiting ready for initiation
Waiting to be Re-matched	Volunteer waiting for re-assignment after a match ends
CLOSED	
CG Closed**	Caregivers discontinued involvement after matching
Vol Closed	Volunteer discontinued involvement after matching
CR Closed***	Care Receiver needs more care, Care Receiver Deceased
Never Matched	

\* CG requests service, in most cases CR assessment conducted, but CR not appropriate for Respite.

\*\* In several cases CGs withdrew from the case BEFORE visits commenced, others closed for CG health reasons.

\*\*\* In several cases the Care Receiver moved to a higher level of care and soon afterward passed away.

<sup>11</sup> Note: per a data request limitation, Community Place did not report number of diverted cases.

**Appendix Table 1: Care Receivers' Medical Challenges**

<i>Number of care receivers with the following conditions:</i>	Total
Alzheimer's (including early onset)	23%
Bed Bound	1%
Broken Hip	1%
Cancer	2%
COPD	4%
Diabetes	27%
FT Dementia	1%
High Blood Pressure	22%
Lewey Body Dementia	1%
Other Dementia	56%
Stroke	8%

\*Note many care receivers had multiple other conditions such as heart disease, depression and anxiety, as well as those listed above.

**Appendix Table 2a: What Do Volunteers Do for CARE RECEIVERS? n=168**

	Never	Occasionally	Frequently
Share a meal or prepare food for him/her	35%	35%	30%
Go on outings	38%	30%	32%
Watch TV with him/her	30%	29%	41%
Play cards or other games with him/ her	68%	18%	15%
Take him/her for a walk or other outing	40%	28%	32%
Provide transportation	52%	25%	23%
Friendly visiting/companionship	5%	10%	85%

**Appendix Table 2b: What Do Volunteers Do for CAREGIVERS? n=168**

	Never	Occasionally	Frequently
Light housekeeping	72%	19%	10%
Yard work/snow removal	94%	5%	1%
Minor home repair	94%	5%	1%
Run errands	80%	12%	8%
Provide listening/support	16%	24%	60%

**Appendix Table 3a: What Do Caregivers Report that Volunteers Do for Care Receivers? n=82**

	Never	Occasionally	Frequently
Friendly visiting/companionship	4%	10%	86%
Go on outings	35%	22%	44%
Provide transportation	55%	23%	22%
Take him/her for a walk	39%	32%	28%
Share a meal or prepare food for him/her	46%	27%	27%
Play cards or other games with him/ her	59%	27%	14%

**Appendix Table 3b: What Do Caregivers Report that Volunteers Do for Them, n=82**

	Never	Occasionally	Frequently
Provide listening/support	28%	20%	52%
Run errands	83%	10%	7%
Light housekeeping	88%	9%	3%
Minor home repair	94%	6%	0
Yard work/snow removal	99%	1%	0

Appendix Table 4a: Powerful Tools for Caregivers Training Results, 2015-16 through 2017-18

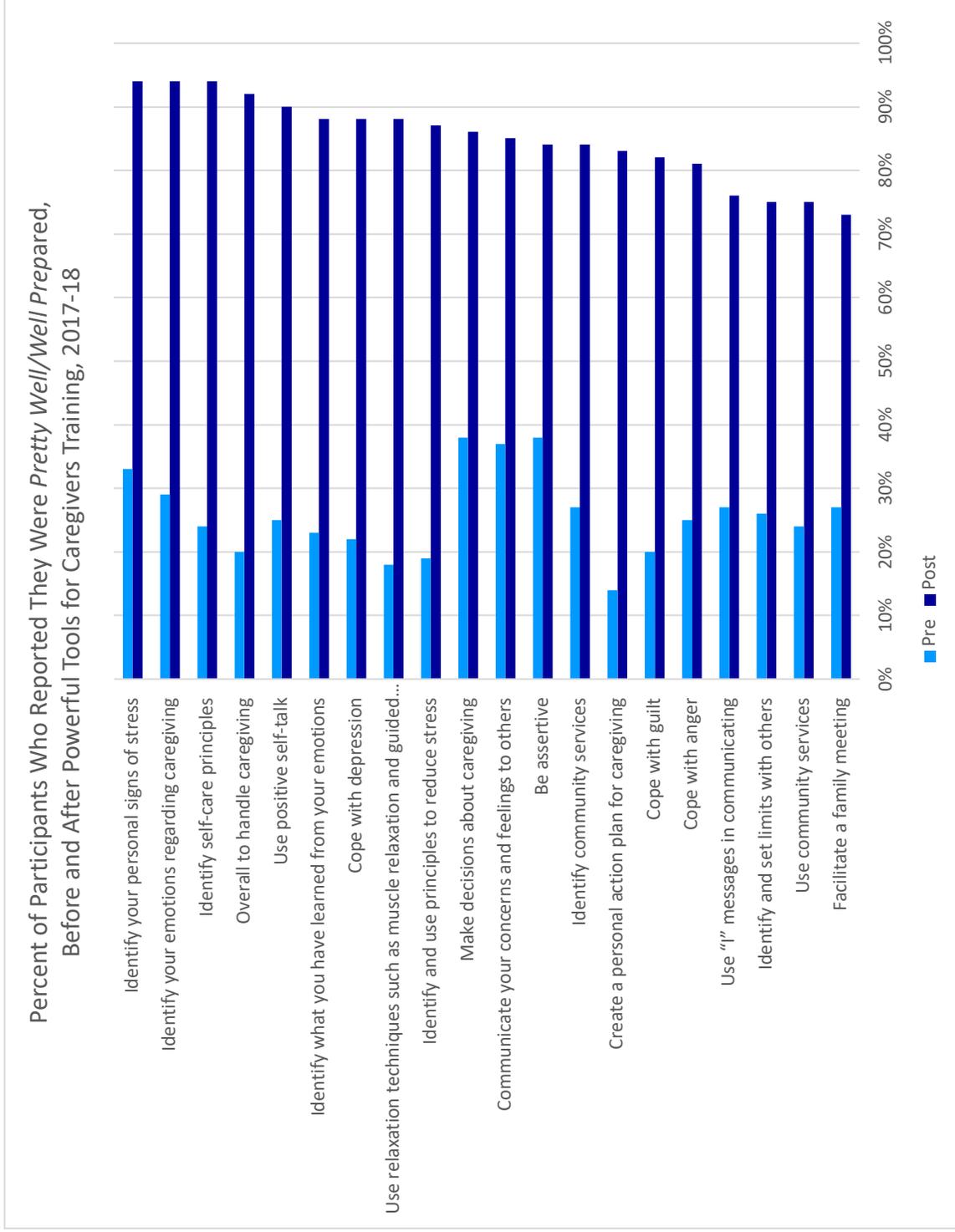
% of Caregivers who reported that they are at least <i>somewhat prepared to . . .</i>	Caregivers 2015-16 n=10	Caregivers 2016-17 n=26	Caregivers 2017-18 n=102
Identify emotions regarding caregiving	100%	96%	100%
Identify what you have learned from your emotions	100%	96%	100%
Overall to handle caregiving	100%	96%	100%
Use positive self-talk	89%	92%	100%
Communicate your concerns and feelings to others	70%	88%	100%
Identify self-care principles for yourself	100%	96%	98%
Identify your personal signs of stress	100%	96%	98%
Identify and use principles to reduce stress	100%	96%	98%
Cope with anger	100%	100%	98%
Cope with guilt	100%	92%	97%
Identify and set limits with others	100%	92%	97%
Cope with depression	100%	92%	97%
Use relaxation techniques such as muscle relaxation and guided imagery	100%	96%	97%
Made decisions about caregiving	90%	92%	97%
Create a personal action plan for caregiving	89%	92%	97%
Use “I” messages in communicating	80%	100%	97%
Be assertive	80%	92%	97%
Facilitate a family meeting	70%	92%	97%
Identify community services	100%	92%	95%
Use community services	90%	92%	93%

Appendix Table 4b: Powerful Tools for Caregivers Training; Pre-Post Results\* (n=52)

% of Caregivers who reported that they are <i>prepared*</i> to . . .	% Pre Training	% Post Training	Change
Overall to handle caregiving	20%	92%	72
Use relaxation techniques such as muscle relaxation and guided imagery	18%	88%	70
Identify self-care principles	24%	94%	70
Create a personal action plan for caregiving	14%	83%	69
Identify and use principles to reduce stress	19%	87%	68
Cope with depression	22%	88%	66
Use positive self-talk	25%	90%	65
Identify what you have learned from your emotions	23%	88%	65
Identify your emotions regarding caregiving	29%	94%	65
Cope with guilt	20%	82%	62
Identify your personal signs of stress	33%	94%	61
Identify community services	27%	84%	57
Cope with anger	25%	81%	56
Use community services	24%	75%	51
Use “I” messages in communicating	27%	76%	49
Identify and set limits with others	26%	75%	49
Make decisions about caregiving	38%	86%	48
Communicate your concerns and feelings to others	37%	85%	48
Facilitate a family meeting	27%	73%	46
Be assertive	38%	84%	46

\*Includes only participants with both pre- and post- surveys, and those who reported they are *pretty well or well prepared*.

Appendix Figure 4c: Pre-Post Analyses, Powerful Tools for Caregivers



Appendix Table 5: Evaluation of Powerful Tools for Caregivers

Caregivers who rated the following as <i>Good</i> or <i>Excellent</i>	2015-16 n=10	2016-17 n=23	2017-18 n=102
Week 1: Introduction to Self-Care Principles, Caregiving Challenges, Action Plans	10	22	96%
Week 2: Identifying Signs and Reducing Stress, Using Positive Self-Talk	10	23	100%
Week 3: Communicating Concerns and Feelings, I/You Messages, Muscle Relaxation	10	23	96%
Week 4: Communication in Challenging Situations; Assertive, Aikido, DESC, Setting Limits, Guided Imagery	10	23	96%
Week 5: Understanding and Learning from Emotions, Dealing with Anger, Guilt and Depression	10	22	100%
Week 6: Mastering Caregiving Decisions: Family Meetings and Futures Planning	10	23	100%
Number of Caregivers who rated the program overall as <i>Good</i> or <i>Excellent</i>	10	23	100%
Number of Caregivers who rated the leaders as <i>Good</i> or <i>Excellent</i>	10	23	100%
Number of Caregivers who indicated that as a result of the class they believe they are more confident caregivers than before taking the class	10	23	100%





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