Social Respite Programs for People Living with Dementia: Volunteer-Led, Community-Driven

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Alzheimer's Association, Western New York Chapter
Impact of Alzheimer’s Disease

5.8 MILLION AMERICANS ARE LIVING WITH ALZHEIMER’S DISEASE.
By 2050, someone in the United States will develop Alzheimer’s dementia EVERY 33 SECONDS.
5.8 million Americans are living with Alzheimer’s. By 2050, this number is projected to rise to nearly 14 million.

More than 16 million Americans provide unpaid care for people with Alzheimer’s or other dementias.
Cost of Dementia vs. Other Conditions

- **Alzheimer's Dementia Patients**
  - Average per-person Medicare cost: $24,122
  - Average per-person Medicaid costs: $7,415
  - Average per-person out-of-pocket costs: $10,315

- **Other Seniors**
  - Average per-person Medicaid costs: $8,399
  - Average per-person out-of-pocket costs: $2,232

Source: Alzheimer's Association
More than 60% are women
Provide care for a longer duration than caregivers of people with other types of conditions.

1/3 of NYS caregivers provide at least 20hrs/week

Are at greater risk for anxiety, depression, and poorer quality of life than caregivers of people with other conditions.

The majority consider caregiving a rewarding experience
What is a Free Community Respite Social Program?

➔ Once per month, volunteer run, four hour social program for individuals living with dementia

➔ Participants ("guests") can socialize, engage in meaningful activities, and share a meal/snack all while building new friendships

➔ Care partners are given time to relax and recharge while they are reassured their loved one is safe

➔ Volunteer to “guest” ratio is 1:1

➔ The majority are at faith-based locations
<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
<th>Location</th>
<th>Lead</th>
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</thead>
<tbody>
<tr>
<td>10:00am</td>
<td>Volunteers Arrive &amp; Set-Up</td>
<td></td>
<td></td>
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<tr>
<td>10:15-10:30am</td>
<td>Welcome Table</td>
<td></td>
<td>Jim &amp; Volunteers</td>
</tr>
<tr>
<td>10:30am</td>
<td>Refreshments &amp; Table Activities</td>
<td>Dining Area (3 tables)</td>
<td>Floaters</td>
</tr>
<tr>
<td>10:55am</td>
<td>Start moving to Sanctuary- front pews</td>
<td></td>
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<tr>
<td>11:00am</td>
<td>Hope Preschool Sings</td>
<td>Sanctuary</td>
<td>Lisa</td>
</tr>
<tr>
<td>11:15am</td>
<td>Craft Time</td>
<td>Carpeted Area Tables (3)</td>
<td>Tom</td>
</tr>
<tr>
<td>11:45am</td>
<td>Restroom Break &amp; Wash Hands</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12:00noon</td>
<td>Lunch</td>
<td>Dining Area</td>
<td>Floaters</td>
</tr>
<tr>
<td>12:30pm</td>
<td>BINGO</td>
<td>Carpeted Area Tables (3)</td>
<td>Randy</td>
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<tr>
<td></td>
<td><em>After Bingo put away tables in carpeted area and make a circle with chairs/sofa area</em></td>
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<tr>
<td>1:00pm</td>
<td>Restroom Break &amp; Wash Hands</td>
<td></td>
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<tr>
<td>1:15pm</td>
<td>Special Activity of the Month</td>
<td>Dining Area Tables (3)</td>
<td>Rachel</td>
</tr>
<tr>
<td>1:30pm</td>
<td>Group Exercise Activity</td>
<td>Carpeted Area Chair Circle</td>
<td>Carolyn</td>
</tr>
<tr>
<td>2:00pm</td>
<td>Sing-A-Long</td>
<td>Carpeted Area Chair Circle</td>
<td>Jenny</td>
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<tr>
<td>2:30pm</td>
<td>Caregiver Pick-Up</td>
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<td></td>
<td><em>Immediately Following: Clean-Up &amp; Debrief</em></td>
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How to Start A Program

➔ **Appropriate space**: Area capable of fitting a group comfortably and is sensitive to the needs of individuals with dementia.

➔ **Coordinator**: One point-person who is willing to take responsibility for managing the program. This person identifies key people to assist and develops a team of volunteers.

**Responsibilities may include:**
- Developing paperwork/admission process
- Interviewing potential participants
- Keeping track of records for participants
- Coordinating volunteers each month
- Checking in with caregivers/participants
- Terminating participant when program is no longer appropriate

*This person can also delegate these responsibilities as they see fit.*
How to Start A Program

➔ **Volunteers** to help with various tasks, including:
  ● Food preparation (if serving food)
  ● Companion with a guest
  ● Activity leader (craft leader, bingo caller, exercise leader)
  ● RSVP calls

➔ **Mandatory Volunteer Training**: All volunteers must be trained through the Alzheimer’s Association, Western New York Chapter
1st hour: Understanding Alzheimer's and Dementia

Volunteers learn about the symptoms of Alzheimer’s disease and other types of dementia, causes and risk factors, and how Alzheimer’s affects the brain.

2nd hour: Sensitivity Simulation

This training helps to provide insight into the sensory changes that may impact someone living with dementia and teach volunteers how to respond in ways that increase their confidence, reduce stress, and enhance the quality of the experience for the individual living with dementia.

3rd hour: Respite Volunteer Specifics

This hour of training teaches volunteers how to engage with a person living with dementia. We discuss how dementia affects a person's ability to engage in activities and how to create a successful respite program.
Management & Support

➔ Support and guidance for starting a program via Lisa Rood (respite consultant) and Director of Respite Services that includes all necessary information, forms, tips, first program visit, and answers to all questions/concerns

➔ Membership in the “Community Respite Coordinator Meetings”

➔ Promotion of the respite program through the Chapter’s social media, program catalog, website, flyers, press releases, ads, and postal mailings to constituents served

➔ Training as needed through the chapter for any new volunteers as well as existing volunteers for refresher purposes

➔ Visits offered to the programs as needed for tips, guidance, and support
Sustainability

➔ $1,000 start-up funds for respite program related materials (crafts, food, independent and group activities, chairs, games, etc.)

➔ Donations and fundraisers (family and congregation donations, in-kind donations through the community, fundraisers in the community)

➔ Initial and sustainability funding through the New York State Office for the Aging (NYSOFA), Erie County Department of Senior Services, New York State Department of Health (NYSDOH), and local foundation grants
Challenges/Barriers

➔ Stigma/expectations of program and perceptions of guests’ needs
➔ Volunteer & guest recruitment
➔ Space
➔ Insurance
➔ Promotion of program and trust-building
➔ Lack of funds for meals and materials
Purpose of Programs:

1. **Socialization for adults living with dementia:** Relationships and ability to initiate activity is greatly diminished with this disease.

2. **Break for care partner:** Many caregivers cannot afford more paid care so volunteer programs serve a great need. Knowing that their loved one is in a safe, fun environment provides peace of mind.

3. **A sense of purpose for volunteers:** Forming bonds with participants (guests) and families, meeting new people, engaging in fun activities, and providing an essential service for people with a terminal illness and their families is fun and rewarding.

There are currently 24 programs running monthly throughout Western New York serving 200+ people living with dementia and their caregivers.
Resources & Support

● Alzheimer’s Association
  ○ 24/7 Helpline 1-800-272-3900
  ○ Support Groups
  ○ Education Classes
  ○ Early Stage Social Engagement
  ○ Professional Training
  ○ Safety
    www.alz.org

● New York State Offices for the Aging
  www.aging.ny.gov

● New York State Department of Health
  https://www.health.ny.gov/diseases/conditions/dementia/help.htm
“The simple act of caring is heroic”

– Edward Albert
Thank you!
THE DALE ASSOCIATION

“Memory Minders” - Minding Your Loved Ones Memory Care
By: Maureen Wendt, President/CEO
“Memory Minders”
A social day program for people with early-mid stage memory impairment.

The program is based on a proven model founded by: Brookdale Foundation
Participants-
Learn techniques to handle issues related to their memory loss.

They enjoy activities and socialization designed to support and engage people with mild memory loss, such as:

- Memory Stimulation
- Physical & Mental Exercises
- Art
- Outings
- Games
- Peer Support
- "Test Kitchen" Fun
- Guest Speakers
- Group Dining
- Themed Curriculum
Family Members-
Appreciate respite time while knowing their loved one is cared for in a safe, supportive and stimulating social day setting.

“My mom is motivated to get herself up and ready to attend Memory Minders, where she feels excited about the day to come. Knowing she is safe and in good hands gives me great piece of mind.”

Janice
What makes Memory Minders work?

- Structured, yet flexible days-themed
- Social or club atmosphere
- Multi-sensory stimulation
- Supportive volunteers
- Screening assessment
- On going support for families
- Safe setting
- Community need for service
- 10am-2pm includes lunch
- Joint enrichment activities with Caregivers
- The Dale Association’s commitment to the continuum of older adult’s needs
Memory Minders Program Assessment

Today's Date: __________  Start Date: __________
Discharge Date: __________ (see discharge report)

Client's Name: ____________________________  Nick Name: __________
Care Givers Name: ____________________________  Care Givers Phone Number: __________

DOB: __________  Age: __________  Preferred Day of the Week: Monday / Friday / Both Days

Ethnicity: ____________________________  Yearly Income: __________
Home Address: ____________________________  Phone Number: __________
Billing Address: ____________________________  Cell Number: __________

Emergency Contact: ____________________________  Phone Number: __________
Is the client a Veteran? Y / N
Physician: ____________________________  Phone Number: __________

Care Factors:

Ambulation
- With assist
- With cane
- With walker

History
- Falls
- Hearing Impaired
- Vision Impairment

Medical Diagnosis
- Forgetful
- Deficient due to dementia
- Other ____________________________

Toileting
- Independent
- Needs Assistance to the bathroom

Diet
- Diabetic
- Regular Diet

Check off as addressed
- Family and Participant toured facility
- Brochure and description of class content discussed
- Billing Procedure
- Grievance Policy

Transportation Source

____________________________
# APRIL 2019

* Programs subject to change *

<table>
<thead>
<tr>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
<th>Thursday</th>
<th>Friday</th>
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<tbody>
<tr>
<td>1*</td>
<td></td>
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<td>5*</td>
</tr>
<tr>
<td><strong>April Fools Day</strong></td>
<td><strong>Can You See the Big Picture?</strong></td>
<td><strong>Virtual Trip</strong>- Elizabethan Times</td>
<td><strong>Easter Egg Coloring Fun</strong></td>
<td><strong>No Class Today on Good Friday</strong></td>
</tr>
<tr>
<td>10 Best Pranks</td>
<td>Funny Names</td>
<td><em>All Things Elizabeth</em></td>
<td><em>Egg-spressions</em></td>
<td></td>
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<tr>
<td>Fact or Folly</td>
<td>Practical Jokes</td>
<td>Tower of London</td>
<td>Guess the Jelly Beans</td>
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</tr>
<tr>
<td>What is April Fools' Day?</td>
<td><em>Funny Mix-Up</em></td>
<td>My Kingdom for a Word</td>
<td>Thank-you Volunteers!!</td>
<td></td>
</tr>
<tr>
<td>Greatest April Fool's Pranks</td>
<td></td>
<td>Life in Elizabethan England</td>
<td>Outcomes Fun w/Jean</td>
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| 8* |           |           |          | 12* |
| **Test Kitchen**-Herb Cheese Knots | **Easter Egg Coloring Fun** | **Easter Egg Coloring Fun** | **Easter Egg Coloring Fun** | **Earth Day /Arbor Day Fun** |
| Splish Splash Detective | Random Trivia | Egg Roll Contest | Egg Roll Contest | Earth Day Family Feud |
| Color My World | *Egg-spressions* | Guess the Jelly Beans | Thank-you Volunteers!! | Decompose Trivia |
| Concentration | *Egg-spressions* | Guess the Jelly Beans | Thank-you Volunteers!! | How Much Do You Know About Earth Day? |
| Take Me Out to the Ballgame | *Egg-spressions* | Guess the Jelly Beans | Thank-you Volunteers!! | Which Word is Misspelled? |
| April Riddle Jumble | *Egg-spressions* | Guess the Jelly Beans | Thank-you Volunteers!! | Forest Funnies |
|                        | *Egg-spressions* | Guess the Jelly Beans | Thank-you Volunteers!! | What Tree am I? |
|                        | *Egg-spressions* | Guess the Jelly Beans | Thank-you Volunteers!! | Tree-Mendous Trivia |

| 15* |           |           |          | 19* |
| **Test Kitchen**-Soft Pretzels | **Easter Egg Coloring Fun** | **Easter Egg Coloring Fun** | **Earth Day /Arbor Day Fun** |
| Wacky Wordies | Cartoon Captions | Egg Roll Contest | Earth Day Family Feud |
| Name 5 | Who said this Slogan | Egg Roll Contest | Earth Day Family Feud |
|        | *Panda-monium* | Egg Roll Contest | Decompose Trivia |
|        | Thank-you Volunteers!! | Egg Roll Contest | How Much Do You Know About Earth Day? |
|        | Thank-you Volunteers!! | Egg Roll Contest | Which Word is Misspelled? |
|        | Thank-you Volunteers!! | Egg Roll Contest | Forest Funnies |
|        | Thank-you Volunteers!! | Egg Roll Contest | What Tree am I? |
|        | Thank-you Volunteers!! | Egg Roll Contest | Tree-Mendous Trivia |

| 22* |           |           |          | 26* |
| **Place the Object Game** | **Earth Day /Arbor Day Fun** | **Earth Day Family Feud** | **Earth Day Family Feud** |
| Remembering Springtime | Decompose Trivia | How Much Do You Know About Earth Day? | Decompose Trivia |
| Easy Does it Trivia | *Decompose Trivia* | Which Word is Misspelled? | Decompose Trivia |
| Wacky Wordies | *Decompose Trivia* | Forest Funnies | Decompose Trivia |
| Group Therapy | *Decompose Trivia* | What Tree am I? | Decompose Trivia |
| Odd Man Out | *Decompose Trivia* | Tree-Mendous Trivia | Decompose Trivia |

29* **Mixed Up Decorating**
- Secret Gardening Quote
- Gardening
- Alphabet Trivia
- Which One is Not Like the Others?
- Flowering Thermometer Craft

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Thank you Volunteers

**Happy Easter!**
<table>
<thead>
<tr>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
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<th>Friday</th>
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<tr>
<td></td>
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<td></td>
<td></td>
<td><strong>3</strong>&lt;br&gt;<strong>Cinco De Mayo</strong>&lt;br&gt;&quot;Test Kitchen&quot;-Mexican Pizza Luncheon&lt;br&gt;History of Cinco De Mayo&lt;br&gt;Squared Up&lt;br&gt;Odd Man Out&lt;br&gt;Cinco De Mayo Secret Message</td>
</tr>
<tr>
<td><strong>6</strong>&lt;br&gt;&quot;Unsolved Mysteries&quot;&lt;br&gt;May IQ&lt;br&gt;Dot to Dot&lt;br&gt;Record Breaking Bubbles&lt;br&gt;Under the Weather/Over the Hill&lt;br&gt;Photographic Memory</td>
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<td><strong>10</strong>&lt;br&gt;<strong>Mother's Day Luncheon</strong>&lt;br&gt;Mommy Dearest Detective&lt;br&gt;Potted Plant Craft&lt;br&gt;Motherly Trivia&lt;br&gt;15 Things Mom Really Meant&lt;br&gt;Mother's Day Pass it On</td>
</tr>
<tr>
<td><strong>13</strong>&lt;br&gt;The Road to Holland&lt;br&gt;Easy Does it Trivia&lt;br&gt;Sky, Land, and Sea&lt;br&gt;Concentration&lt;br&gt;Odd Man Out</td>
<td></td>
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<td><strong>17</strong>&lt;br&gt;<strong>Road Trip Fun</strong>&lt;br&gt;The Botanical Road Show&lt;br&gt;Car Emblem Game&lt;br&gt;Road Trip Trivia&lt;br&gt;Drawing a Blank&lt;br&gt;Mad Science&lt;br&gt;RVing in Winnipeg&lt;br&gt;Virtual Tour</td>
</tr>
</tbody>
</table>
| **20**<br>Red Moon Road<br>Alphabet Trivia<br>Who Am I?<br>Group Therapy<br>Finish the Food Idiom<br>Architecture Mining |              |           |          | **24**<br>**Memorial Day Remembrance**<br>Inside these Hallowed Grounds<br>Common Bond<br>Holiday—"Price is Right"
| Thank you Volunteers |              |           |          | **31**<br>**Double Exposure**<br>Random Trivia<br>Concentration<br>Anagrams<br>Double Trouble<br>This & That<br>Wacky Wordies<br>What do they have in Common? |

*M Programs subject to change*
3*

Cinco De Mayo

‘Test Kitchen’-Mexican

Pizza Luncheon

Squared Up

History of Cinco De Mayo

Odd Man Out

Cinco De Mayo

Secret Message
Why Beneficial?

**Recipient-**
- Stimulating - reminisce, bake, craft and remember
- With peers in a social setting
- Fun
- Safe

**Caregiver-**
- Respite
- Resources and Support
- Safety
Annual Surveys consistently show caregivers “strongly agree” or “agree” that Memory Minders improves the quality of life for their family member.
Challenges and Barriers

• Transportation to/from service
• Cost
• Overcoming “denial” by recipient
• Caregivers wait too long to seek services—loved one’s dementia more advanced than they realize
What Questions to Ask?

• How will this program help my loved one?
• How will this program help me as a caregiver?
• How is my loved one evaluated? /Re-evaluated?
• What is the best way to communicate with leader?
• What is a typical day/activities?
• Is there a trial period? /Can I observe?
• Is transportation provided/available if needed?
• Logistical questions-time, days, size of class, leader/volunteer participant ratio and holidays?
• Cost/payment arrangements
• Do Leaders and/or Volunteers get special training for work with Dementia population?
Sustainability -

• Brookdale Foundation “seed money” year one and year two

• Office for Aging funding-annually

• Participation Fees

• Donations

• Memory Minders is one of many other services offered by The Dale Association

• Exploring Insurance Reimbursement.
Questions
Contact us!

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Rachel Rotach rrotach@alz.org