



# Memory Matters

January • February • March 2007

## One Disease — Several Means of Support

Alzheimer's disease is not a journey you should travel alone. As much as you may not feel comfortable asking for help, this truly is the time to not only ask, but welcome assistance or support of any kind.

“Support” may mean something different for each one of us. You may be the perfect candidate for a support group where you can meet regularly with others in similar situations to share experiences and encourage one another. But someone else in your shoes may shy away from groups of people, feeling overwhelmed with sharing anything, let alone the very personal struggle a disease like Alzheimer's presents. The bottom line is that no one is going to react exactly like the next person when faced with a diagnosis of Alzheimer's, or when caring for a loved one with the disease...and that is perfectly normal.

The Heart of America Chapter offers a variety of support resources and you may find that what works for you today may not be the kind of support you need a month from now. We encourage you to try different avenues of support to see what helps you.

### Support Groups

Support groups offer a regular, safe place for family members and friends to meet and share information and provide support to one another. Support group members report many benefits including:

- Understanding the behavior of the individual with Alzheimer's
- Receiving validation for negative or ambivalent feelings
- Feeling “I'm not alone” and receiving emotional support
- Learning specific strategies to handle their loved one's behavior
- Receiving encouragement to maintain or regain their personal lives

Participation in a support group may help to normalize the experience of caregiving and decrease feelings of burden, even when the person with Alzheimer's continues to deteriorate and the demands on the caregiver increase. Support groups also aid the family in making the transition to outside care a more positive experience.

*See Support on page 3*

## Heart of America Chapter and the Mollie Tivol Alzheimer's Family Resource Center

### INSIDE FEATURES

Support Mechanisms ... Front Cover,	3
Unexpected Heroes .....	2
New Resource Center Materials.....	3
Save These Dates.....	4
Maintain Your Brain™.....	4
Questions and Answers 101.....	5
Diabetes and Alzheimer's.....	6
Responding to Behavior.....	6
Calendar of Events.....	7
General Contribution Form .....	Back Cover

### ONLINE NEWSLETTER

This newsletter is also available online. You can access this issue or past newsletter issues by logging on to [www.alz-heartofamerica.org](http://www.alz-heartofamerica.org) and clicking on the link in the red box on the home page.

Or, if you prefer the newsletter in print and are not currently a subscriber, fill out the form online or call 913-831-3888.

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## The Unexpected Heroes

by Juliette B. Bradley, Communications Director

I have had a career my entire adult life. I was never sure, however, if my children really understood what I do. My oldest son is now in college and has a clear picture of how I spend my days. My 9-year old son, Kit, has tagged along to fundraisers, asks occasional questions and seems to be satisfied with my brief answers. But to my surprise, he showed me he understands far more than I could have ever expected.

Kit told me that his 4th grade class was going to learn about a business...an ice cream shop. A local shop would mentor their class and teach them about the daily functions and how to do business in a community. At the end of the semester, the children would create a mock ice cream shop in their classroom, invite friends and family and serve ice cream, charging a nominal fee. Money raised would be donated to a local charity, chosen by the class.

The next day Kit came home from school and announced that he suggested to his class that the ice cream shop money be donated to the Alzheimer's Association. I was of course very touched that he would make such a suggestion, but a bit surprised none the less, as it seemed like such a grown up thing to do. Let's be honest, Alzheimer's isn't the first thing on a 9-year old's mind....or is it?

Next Kit told me that the class had narrowed the selection down to two organizations. The Alzheimer's Association and The Humane Society. At that point when I imagined 4th graders talking about a dreadful disease compared to cute, warm, furry puppies and kitties, well I didn't think that we stood a chance to earn their donation.

The teacher invited me in to talk to the kids and explain what our organization did so they could make their final decision. I asked the class if anyone had ever heard of Alzheimer's. A very eager boy immediately raised his hand and said "Yes, my mom has it." I paused, and continued on. Not only was Alzheimer's on the mind of this little boy that day, but every day, all day. He was far more experienced than I had ever given him, or any other 9-year old, credit for.

The boys and girls chose to support their classmate, and donated to the Alzheimer's Association. They presented our Chapter with a check for more than \$200. That was hundreds of scoops of ice cream.

Yes, the \$200 was a welcome contribution to our organization, but what also made a great impact was how these kids supported a classmate in need. Their small but mighty gesture reminds us that

everyone can make a difference in the fight against Alzheimer's. These kids are my heroes! I know I will never again doubt the experience of a 9-year old.



Kit Bradley stands next to his teacher, Mrs. Karen McBride, and the rest of his 2006 4th grade class at Indian Valley Elementary School in Overland Park.

## Support continued from Front Cover

More than 60 support groups meet regularly in our Chapter service area. Whether you are a caregiving spouse or an adult child of someone with Alzheimer's, there is a support group for you. To check the complete listing of support groups, please logon to the Chapter website at [www.alz-heartofamerica.org](http://www.alz-heartofamerica.org) and click on "Support Groups" in the left hand margin of the home page.

Another option, similar to a support group, is a Breakfast Club meeting. This is a hometown experience where people gather in a safe environment and where support is provided in a round table way. Breakfast Clubs meet monthly in Chanute, Fort Scott, Parsons, and Pittsburg, KS, and Kansas City, St. Joseph, and Trenton, MO.

### One-on-One Visit With a Family Services Specialist

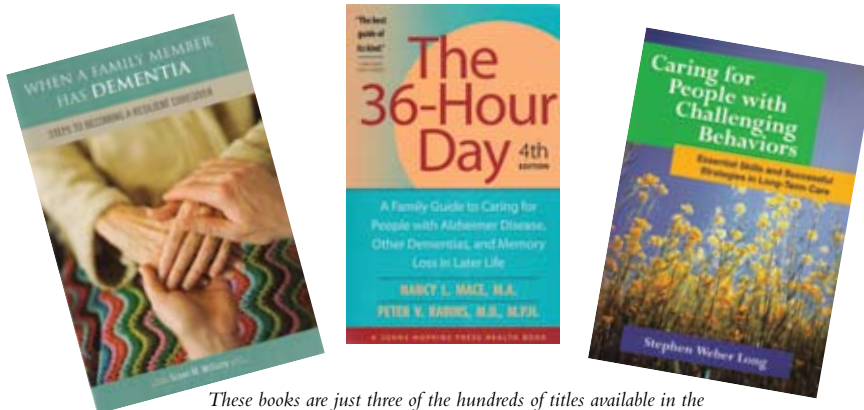
Families have many questions and concerns about Alzheimer's disease and often just need someone to talk to. Our Chapter staff welcomes your questions and concerns and their flexibility allows them to come to you for a visit or you can meet one of them at the Chapter office. Of course, if a phone meeting works better for your schedule, you can always phone to discuss your situation. Their services, like all family services of our Chapter, are free of charge.

### Information, Assistance and Referral

Our toll free number, 800-272-3900, is answered by Alzheimer's Association staff 24-hours a day, 7 days a week. The 24-hour Information and Support Line is available to answer your questions and to offer support and advice.

### Books, Videos and Brochures

We are honored to house the Mollie Tivol Alzheimer's Family Resource Center in our main Chapter office. Here you will find up-to-date books, videos, brochures and other material that you can borrow or purchase so that you can read at your own pace, either in our library or in the privacy of your home. New titles are added regularly so it is a good idea to check every few weeks to see what is new. All regional offices have access to these resources and also offer a variety of informative material at their locations.



*These books are just three of the hundreds of titles available in the Mollie Tivol Alzheimer's Family Resource Center. The center is open 8:30 a.m. to 5:00 p.m. Monday through Friday.*

The most recent additions to the Mollie Tivol Alzheimer's Family Resource Center are listed below. Stop by during regular office hours to review our new material.

- 100 Questions & Answers About Alzheimer's Disease
- A Caregiver's Guide to Alzheimer's Disease: 300 Tips for Making Life Easier
- Alzheimer's A to Z
- Alzheimer's Disease
- Assessing Older People
- Caring for People with Challenging Behaviors
- Courage to Care: A Caregiver's Guide Through Each Stage of Alzheimer's
- Montessori-Based Activities for Persons with Dementia (V.2)
- Movement with Meaning: A Multisensory Program for Individuals with Early-Stage Alzheimer's Disease
- Promoting Family Involvement in Long-Term Care Settings
- Speaking Our Minds: Personal Reflections from Individuals with Alzheimer's
- Strengthen Your Mind: Activities for People with Early Memory Loss
- The 36-Hour Day (New 4th edition)
- The Alzheimer's Sourcebook for Caregivers
- The Caring Spirit Approach to Eldercare
- The Complete Guide to Alzheimer's Proofing Your Home
- Voices of Alzheimer's
- When a Family Member has Dementia: Steps to Becoming a Resilient Caregiver



## Questions and Answers 101

by Jeanne Reeder, L.M.S.W., Individual and Family Services Specialist

Listen in to some recent questions asked on a typical day at the chapter office:

*“Can you tell me some care facilities I can go look at? I don’t want Max to be placed, but the kids are convinced that caring for him is too much for me. I think I will know when I cannot take care of him. I am sorry to bother you, but I will go look in case that day does come.”*



Jeanne Reeder, L.M.S.W.

*“I just have a quick question. Minnie sits all day and sleeps, but at night she is wide awake, is this typical of Alzheimer’s disease?”*

*“I know you are busy, and my Mom is Dad’s caregiver, but does this sound like Alzheimer’s disease to you? Yesterday he told the grandkids to go home, to get out of here. Do you think something else may be wrong?”*

These questions, and there are many others, come from caring people who want the best answer, or should I say, the answer, for the person they love. Such questions may come from the primary caregiver, an adult child, or another relative or friend who also helps care for the person with Alzheimer’s disease/dementia. But answers to the majority of questions that caregivers ask on a daily basis are seldom, if ever, one-liners, and very few can be answered in twenty-five words or less.

If I were the David Letterman of Alzheimer’s disease, I would quickly develop lists of the top ten questions about Alzheimer’s disease with answers that would put a smile on every caregiver’s face. But you and I know that life and caregiving are more complicated than Letterman’s humor. Sometimes, this quotation from Gertrude Stein is closer to the truth: “There ain’t no answer. There ain’t gonna be any answer. That’s the answer.”

But not entirely. Somewhere in the middle between Dave Letterman and Gertrude Stein are helpful answers for caregivers and families. When caregivers don’t hear these answers, they feel inadequate, vulnerable, or stressed — feelings that may lead to more stress, family problems, or caregiver burnout.

Questions are an integral part of the caregiving journey. Primary caregivers and other family members are courageously navigating the unmapped peaks and valleys of this disease. And 70 percent or more of people

with Alzheimer’s/dementia are cared for in their home by family members walking this path alone. The questions they ask help smooth the way for other travelers and make the journey more comfortable. Here are some do’s and don’ts that may encourage you to continue your search for answers.

Do not apologize for asking questions. Instead, pat yourself on the back every time you ask a question. Educating yourself and your family about this disease may be your best, most powerful tool. Remember what they told you in grade school: knowledge is power, and there are no wrong or stupid questions. This truth still holds true.

Do not be afraid to ask questions. The technique that worked for your boss’s mother may or may not work for your aunt. Just because someone else managed Dad at home for thirteen years, does not mean that you are a poor caregiver if your family places Dad three years after his diagnosis. Every person with Alzheimer’s/dementia can and often does experience a range of different symptoms. The progression of the disease and your loved one’s personal response to the disease will not always unfold in predictable or standard ways.

Do know that your questions will yield more than one answer. Answers may be more or less certain, more or less adequate, whether the caregiver is asking why George or Tina is exhibiting a particular behavior or whether it is time to move your loved one into residential care. Be flexible and open to looking at various options; then, choose the option that works best for your loved one and you. And make your choice happily, despite the nagging voice that says, “it won’t work with my Dad.” You could be pleasantly surprised, and if it doesn’t work, you will be free to try the next idea.

Above all, do not hesitate to ask as many questions as occur to you, and as often as they occur. You will be pleasantly surprised at how eager many people will be to listen to your concerns. You can ask questions of the Alzheimer’s Association by calling us at 913.831.3888 or 1.800.272.3900. You are the reason we are here, and we are honored to be a small part of your journey.

Your doctor may be the best person to answer your questions regarding the disease or medications, and people in your faith community may help you deal with more personal and spiritual matters. Finally, if you do not already belong to a support group, you may want to consider joining one this year. Support group members are ready listeners, and your question may be just the one that someone else is longing to ask. Peace and comfort are found as often in seeking as in finding.

## Studies Focus on Link Between Diabetes and Alzheimer's

Studies show that there's an increased link between Alzheimer's disease and diabetes, which is largely preventable through diet and exercise. With an estimated 18 million Americans with Type 2 diabetes and another 41 million with pre-diabetes, a vast number may be at risk.

It's unclear why high blood sugar or uncontrolled insulin levels can cause massive brain cell death or whether the pathology of diabetes is a minor or major cause of dementia.

Diabetes and high blood pressure, major risk factors for heart disease that often are found together, may affect blood vessels in the brain – similar to their effect on the heart's arteries – and cause mini-strokes and vascular dementia.

Another theory is that people with high blood sugar develop insulin resistance, which may lower the levels of insulin in the brain in tandem with higher insulin levels in other parts of the body. So, brain cells that may not get enough glucose develop increased inflammation that builds up beta-amyloid and causes brain cells to die.

And still another idea is that high insulin levels compete with enzymes that break down beta-amyloid, which produces high levels of the protein in the brain.

A new study at the University of Wisconsin – Madison is testing blood sugar and insulin in as many as 900 people who have at least one parent with Alzheimer's. Many other studies are under way worldwide to study the ties between diabetes and Alzheimer's.

## Responding to Alzheimer's Behaviors

People with Alzheimer's disease may act in different and unpredictable ways. Some become anxious or aggressive. Others repeat certain questions or gestures. Many misinterpret what they hear.

These reactions can lead to misunderstanding, frustration and tension, particularly between the affected individual and the caregiver. Understand that the person is not acting that way on purpose.

Here are ideas for how to respond to these behaviors:

- Remain flexible, patient and calm.
- Respond to the emotion, not the behavior.
- Don't argue or try to persuade.
- Use memory aids.
- Acknowledge and respond to requests.
- Look for the reasons behind each behavior.
- Ask a physician to identify any causes related to medications or illness.
- Explore various solutions.
- Don't take the behavior personally.
- Share your experiences with others.

If you have questions about your loved one's changing behavior, contact the Alzheimer's Association – Heart of America Chapter at 913-831-3888 or 800-272-3900.

### Brain Teaser ANSWERS

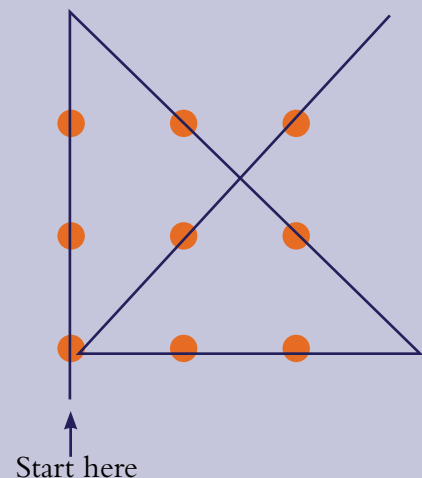
From Teasers on Page 4

#### COMPLETE THE WORD

DENTURES  
TRIDENT  
DENTISTRY  
INDENTATION

#### 4 STRAIGHT LINES

Hint: Think "outside" the box



## Heart of America Chapter Calendar of Events

January • February • March

### BREAKFAST CLUBS

*A hometown support experience where people gather in a safe environment and where support is provided in a round table way.*

#### Chanute, Kansas

The first Wednesday of every month  
Holiday Park Restaurant, 9:00 – 10:30 a.m.

#### Fort Scott, Kansas

The third Wednesday of every month  
Mercy Hospital, The Xavier Room, 9:00 – 10:30 a.m.

#### Parsons, Kansas

The first Thursday of every month  
The Bake and Bean, 105 S. 18th, 9:00 – 10:30 a.m.

#### Pittsburg, Kansas

The third Thursday of every month  
Mount Carmel Hospital — The Sheridan Room  
9:00 – 10:30 a.m.

#### Kansas City, Missouri

The second Saturday of every month  
St. Louis Center, 5930 Swope Parkway, 9:30 – 11:30 a.m.

#### St. Joseph, Missouri

The third Wednesday of every month  
Francis Street United Methodist Church, 12th & Faraon  
9:00 – 10:30 a.m. \$5 Fee

#### Trenton, Missouri

The first Wednesday of every month  
Lakeview Restaurant, 9:00 – 10:30 a.m.

### OTHER IMPORTANT DATES

#### January 10 – Building Creative Dementia Caregivers: A Train the Trainer Approach

*This program is geared toward individuals in facilities/agencies that are charged with educating others about the illness.*

Topeka Presbyterian Manor, Multipurpose Room  
4712 Southwest 6th Avenue  
Topeka, KS

9:00 a.m. – 3:00 p.m.

Fee \$65 per person, \$40.00 for each additional person from the same organization. Participants will receive a dementia training manual and certificate of attendance.

#### January 25 – The Role of Activities in Culture Change

*Activities play a significant role in quality of life, in understanding residents and in supporting capacity. This workshop discusses the philosophy behind activities and offers numerous examples of ways to incorporate these activities in day to day life. Each participant will receive a certificate of attendance.*

Overland Park, KS

Contact Main Chapter Office at 913-831-3888 for location

9:00 a.m. – 4:00 p.m.

Cost \$40.00

#### February 20 – Building Effective Skills Training (B.E.S.T.)

*Specifically for nursing assistants, recreational and activity aides in extended care and community setting. Participants will receive certificates of attendance.*

Main Chapter Office, 3846 W. 75th St., Prairie Village, KS  
8:30 a.m. – 3:30 p.m. Fee \$25

#### March 1 – All About Alzheimer’s Disease

*A program for all individuals interested in memory loss issues. Discussion will focus on general disease information including diagnosis, stages, risk factors, current treatments and interventions.*

Carrollton Senior Center  
200 Life Care Lane, Carrollton, MO  
6:30 – 8:00 p.m.

#### March 12 and March 19 – ABC’s – Alzheimer’s Basic Care

*An overview of the disease process — how family caregivers can work with the individual experiencing the disease. Additional topics covered include communication, behaviors, and feelings.*

Topeka, KS — Call Northeast Kansas Regional Office at  
785-271-1844 for details.

#### March 27 – All About Alzheimer’s Disease

*See description on March 1*

Clinton Senior Center  
970 East Sedalia, Clinton, MO  
6:30 – 8:00 p.m.

**Please Note** – All meetings/classes are free of charge unless otherwise noted. All regional offices of the Heart of America Chapter host meetings and classes. Please note if the meeting/class you are interested in is held in Kansas City, Topeka, or St. Joe. The Alzheimer’s Association Heart of America Chapter Main Office is located at: 3846 W. 75th Street, Prairie Village, KS; The office sits behind the Reece & Nichols real estate building on the Northeast corner of 75th Street and Mission Road. Registration for all meetings/classes is highly recommended and sometimes required if noted. Unless otherwise noted, call 913-831-3888 to register. Meeting times and locations are subject to change.

### Memory Matters

is a quarterly publication of the  
**Alzheimer’s Association – Heart of America Chapter**

**24-hour Information & Support Line 800.272.3900**  
**www.alz-heartofamerica.org**

#### Main Office

3846 W. 75th Street, Prairie Village, KS 66208  
913.831.3888 FAX 913.831.1916

#### Midtown Satellite Office

6400 Prospect, West Building, Suite 640B  
Kansas City, MO 64132  
816.361.6604 FAX 816.361.6627

#### Northeast Kansas Regional Office

4125 SW Gage Center Drive, Suite LL-15  
Topeka, KS 66604  
785.271.1844 FAX 785.271.1804

#### Northwest Missouri Regional Office

10th and Faraon, St. Joseph, MO 64501  
816.364.4467 FAX 816.364.2553

#### Southeast Kansas Office

UCDD Building, 2601 Gabriel  
Parsons, KS 67357  
620.421.6550 ext. 1794 FAX 620.421.0671

RETURN SERVICE REQUESTED



**Mission Statement:**

*To provide education and leadership to enhance care and support services for those affected by Alzheimer's disease while supporting efforts to eliminate the disease.*

**GENERAL CONTRIBUTION FORM**

**Yes! I want to help the thousands of area families affected by Alzheimer's disease!**

Enclosed is my tax-deductible contribution of \$ \_\_\_\_\_.

Check Enclosed (payable to Alzheimer's Association)  Visa  MasterCard Card # \_\_\_\_\_ Exp Date \_\_\_\_\_

Card Holder's Name \_\_\_\_\_ Signature \_\_\_\_\_

Please print, and include salutation (Mr. & Mrs., Dr., Mr., Mrs., Ms.) Donor Name \_\_\_\_\_

Address \_\_\_\_\_ City \_\_\_\_\_ State \_\_\_\_\_ ZIP \_\_\_\_\_

Home Phone \_\_\_\_\_ Work Phone \_\_\_\_\_

My gift is given:  In Memory of \_\_\_\_\_  In Honor of \_\_\_\_\_

Special Occasion \_\_\_\_\_ (birthday, anniversary, congratulations, etc.)

Please notify: Name \_\_\_\_\_

Address \_\_\_\_\_ City \_\_\_\_\_ State \_\_\_\_\_ ZIP \_\_\_\_\_

Please send me information about:  Volunteering  Providing for the Alzheimer's Association in my will

I have made a gift to the Alzheimer's Association in my will  My employer has a matching gift program, form enclosed

**Please return to: Heart of America Chapter • 3846 W. 75th Street • Prairie Village, KS 66208  
For more information call the Chapter office: 913-831-3888 or 800-272-3900**