



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

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*Memory Matters*

*January • February • March 2004*

**Celebration of First Spirit Garden  
Shows Fruits of Labor**

When Alzheimer's disease is a focus in the media, the attention typically is driven by new information on research advancements, medications on the horizon, and possible new treatments. All of this information is vital and certainly newsworthy. However, it is imperative that every effort be made to acknowledge those who actually are stricken with the disease. The Chapter's efforts to help preserve the dignity of all those with Alzheimer's is equally important as the medical issues of the disease.

That is why it was with great honor and pleasure that the Alzheimer's Association – Heart of America Chapter celebrated the opening of the first of what will hopefully be many Spirit Gardens.

*continued on page 3*



*Pat Coleman, Finance Director of the Alzheimer's Association - Heart of America Chapter, shares the ribbon cutting privilege with Mary Ellen Joslyn, Senior Unit Social Worker, to celebrate the opening of the first Spirit Garden for those with dementia.*

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## A New Year's Wish: May Our Paths Cross Often

*by Debra R. Leib, Executive Director*

'Tis the season  
to write in rhyme  
And celebrate  
this holiday time

To reflect upon  
the year that's past  
To honor those  
whose spirits last

And reinforce  
what matters most  
It's the life we live  
not the things we boast

It's how we choose  
to live each day  
That will be remembered  
long after our stay

This dreaded disease  
that takes its toll  
May rob the mind  
but not the soul

So with each day  
we're given a choice  
To lend our hand  
or perhaps our voice

In so many lives  
a difference we make  
I ask you to think  
with each step that we take

Have we done all we can  
to ease a friend's sorrow  
Have we said to a loved one  
"Let's not wait 'til tomorrow"

For soon we will make  
resolutions anew  
We're often asked  
"What can we do?"

To bring us closer  
to realizing our vision  
Of a world without Alzheimer's  
or enhancing our mission

Increasing services and support  
to all those in need  
Throughout our newsletters  
I know that you read

Of our successes and programs  
which we cannot do  
Without help and support  
from readers like you

Thanks we offer  
to our donors and friends  
And our faithful volunteers  
whose great spirit lends

A message of hope  
and of love and of care  
That with each dollar given  
or each hour shared

We make lives that we touch  
much brighter by far  
And speak volumes about  
the people we are

And so we offer  
good tidings and cheer  
May our paths cross often  
in a joyful new year.

## Memory Matters

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Heart of America Chapter**

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## Spirit Garden Celebration To Be First of Many

*continued from page 1*

In conjunction with Research Psychiatric Center, and many generous sponsors, the first Spirit Garden opened on November 18th, 2003 at the Research facility in Kansas City, MO. A reception followed the official ribbon cutting ceremony where guests could walk the meandering path, rest at the meditative benches, see the beautiful trees and experience the quiet places in the courtyard.

Michelle Niedens, Heart of America Chapter Education Director, spoke eloquently at the reception about the meaning of the Spirit Garden. She said, "The Spirit Garden honors the priceless value of simplicity, the peacefulness of the good earth and the sounds and sights that bring comfort." She continued by sharing words of inspiration from a friend with Alzheimer's who spoke at Missouri Memory Day earlier this year. "Don't rule me out. Just because I have Alzheimer's disease doesn't mean that I no longer count." Michelle reminded us that we have the responsibility to acknowledge someone with Alzheimer's as a person, and that we have no permission to forget that each one of us does play a role in how someone walks through this illness.



*These benches provide a peaceful resting place along the meandering path of the Spirit Garden.*

Unless you experience Alzheimer's first hand, it is easy to look the other way, to ignore the pain of the disease. But we are reminded we do not have permission to do so,



*Debra Leib, Executive Director; Pat Coleman, Finance Director; and Michelle Niedens, Education Director of the Alzheimer's Association - Heart of America Chapter; joined Todd Krass, CEO, Research Psychiatric Center; to celebrate the opening of the first Spirit Garden.*

and we can most definitely not give up. Because no matter how hard we work, the person with the illness has to work even harder. The Spirit Garden is about not giving up.

Profound gratitude goes to donors who opened their eyes and resources to this project including: The Sunderland Foundation and Butler Manufacturing, and those who supported the project with in-kind donations or reduced costs including: Heartland Nursery, First Deck, Kincade and Company, Van Liew's Statuary, Family Tree Nursery and Brighter Landscape Lighting.

A special thank you goes to the Research Psychiatric Center Plant Operations Department, the HCA grounds crew, and the direct care staff.

Because of Michelle's vision and the belief others had in it, the Spirit Garden is now in place. As Michelle concluded in her remarks, "Believing that while the microscope will bring us the cure, it can not bring us good care." Her words engraved in the minds and hearts of all at the reception that no matter how vicious the disease is on the mind and body, the spirit is indestructible.



## Tivol Legacy Continues to Support Association

If you are a regular reader of *Memory Matters* newsletter, or if you frequent any Heart of America Chapter fundraising events, you have probably seen the *Tivol* name appear in many situations. Perhaps you have visited The Mollie Tivol Alzheimer's Family Resource Center in our Chapter office or attended the Tivol Golf Classic. It is not uncommon to be asked how the relationship between the Tivol family and the Alzheimer's Association – Heart of America Chapter unfolded.

In 1990, Mollie Tivol was diagnosed with Alzheimer's. Her son, Harold Tivol, owned and operated *Tivol*, an upscale jewelry store on the Country Club Plaza in Kansas City, MO. Harold's father began the jewelry business in 1910 and Harold, his son, Tom, and his daughter, Cathy, followed in the family business.

Harold and his family were fortunate enough to be able to care for Mollie in their home by hiring private nurses to be with her all hours of the day. Even when moving Mollie to a special care facility was necessary, Harold still insisted on the private nurses. But Alzheimer's knows no boundaries. It affects people of all races, economic status and ethnic backgrounds. Harold's wife, Ruthie, was curious what support system was in place to help those who may not have the resources to take care of their loved one at home. They wondered how other local families were coping with the stress, the financial hardship, and the emotional strains of caring for a loved one with Alzheimer's.

Harold and Ruthie found out first hand. They visited what was then a very small Alzheimer's Association, housed in a less than perfect

building, "somewhere under a Chinese restaurant," Harold remembers.

He said it was instantly clear to him and Ruthie what the Association needed — a place to call home. "The organization couldn't help families in that kind of environment — they needed space — somewhere they could set up a real office." And in Harold's natural way, he saw a need and he

responded by assisting in finding and financing the current home of the Chapter office.


"We were lucky," Harold claims. "Caring for someone with Alzheimer's can be a lonely time. We had people around the clock to help us out, but most people don't. We wanted to do something to make a difference for other families."



*Tom, Cathy and Harold Tivol surrounding a photograph of Harold's mother, Mollie Tivol*

The Tivols continue to make a difference. On December 13, 2003 they hosted a benefit for customers of their Plaza and Hawthorne locations at Starlight Theatre. Entertainer Jim Belushi presented an evening concert where all proceeds benefitted the Alzheimer's Association.

"We all hope for medical breakthroughs. But for now, we have to do the best we can and the Chapter is the best place to turn for support." Harold said.

We offer a hearty **THANK YOU** to the entire Tivol family for honoring Mollie in this way, and to their customers for supporting the efforts of the Alzheimer's Association – Heart of America Chapter over the years. You can rest assured knowing we are doing the very best we can to provide needed programs and services to support all those suffering the physical, emotional and financial challenges of Alzheimer's disease. 

## PBS Initiative Turns Spotlight on Alzheimer's Disease

On Wednesday, January 21 at 7:00 p.m. KCPT Public Television presents a groundbreaking evening of programming that will bring the looming health crisis of Alzheimer's disease to national attention offering insight, context, help and hope.

The evening begins with *THE FORGETTING: A Portrait of Alzheimer's*, a 90-minute documentary that explores this frightening disease, the human toll it takes on patients and caregivers, and the latest research in the race to find a cure.

Following the broadcast at 8:30 p.m. KCPT presents *ALZHEIMER'S: The Help You Need*, an hour-long live call-in special that will bring together a panel of experts to provide authoritative answers to commonly-asked questions and direct viewers to organizations and resources that can offer help and support.

*THE FORGETTING: A Portrait of Alzheimer's* marks the first major PBS initiative on Alzheimer's disease. The landmark program, produced and directed by Elizabeth Arledge, was based on the best-selling book *The Forgetting — Alzheimer's: Portrait of an Epidemic*, by David Shenk, who served as a consultant to the documentary and appears in it.

"This is a disease that simply cannot be ignored," says Naomi Boak, Executive Producer of THE FORGETTING.

## THE FORGETTING

January 21

7:00 p.m.

KCPT Public Television

Channel 19 Kansas City and St. Joe

KTWU Channel 11 Topeka

## Council Grove Hosts Alzheimer's and Dementia Awareness Event

Sponsors Council Grove HealthCare Center and Morris County Hospital hosted an Alzheimer's and Dementia Awareness Day on November 8th to educate the public about Alzheimer's disease and related dementias. Jennifer Haller, Program Coordinator for the Alzheimer's Association – Heart of America Chapter Topeka office, was on site to visit with community members, answer questions and distribute educational materials.

Alzheimer's and Dementia Awareness Day also featured three large gift baskets which were raffled at the close of the session. The theme baskets featured Kansas State University, Take it Easy stress relief, and Decorating for the Holidays. Proceeds from the raffle also benefited the Alzheimer's Association.

The event grossed approximately \$800 to help support the services of the Alzheimer's Association – Heart of America Chapter. An especially warm "thank you," is extended to organizers Elisha Smith, Paula Gant, Virginia McDiffett, and Carolyn and Richard VonFeldt.



Nancy Tillman, caregiver and volunteer (right), visited with a guest at the Alzheimer's Awareness day held at the Satellite office in Kansas City, MO on November 6th. Guests were presented with disease information, screening and diagnosis information, and prescription drug discount information.

## Glad You Asked

This column features a question from a caregiver, family member or patient who is searching for ideas or suggestions. You can submit a question to Jeanne Reeder, LMSW, Patient and Family Services Specialist, at the Heart of America Chapter office, 913-831-3888, or e-mail [jeanne.reeder@alz.org](mailto:jeanne.reeder@alz.org).

**Question:** *“Dad doesn’t want to do anything lately. How can we get him off the couch and involved in some activity?”*


**Answer:** As a caregiver there are some basic things you need to know about activity in general. Activities are any motions, mental or physical, that enhance our lives, give us meaning and purpose, and keep us healthy. Of course, this definition includes routine tasks, such as getting dressed, meal preparation and eating as well as music, art, movies, and games. Activity is good for everyone because it keeps our bodies moving, stimulates our minds, enhances our self worth, provides a sense of purpose and reduces behavior problems.

There are also many reasons why people with dementia withdraw from activities. Sometimes, especially in early stage, the person may become upset, angry, frustrated or even depressed because they have attempted to do something and failed or cannot recall how to do a once simple activity. Perhaps the person could once do activities requiring multitasking, but those are difficult for the person with dementia. Another reason people with dementia withdraw from activity is because loving and caring people sometimes jump in the middle and do their tasks or activities for them. If that is the case, they might be thinking, “Why should I bother to do it — she’ll just do it for me.” Still another reason is that the loss of a very meaningful activity — for example, employment or driving — creates the idea that all is lost, so why do anything?

Here are a few simple things to keep in mind when planning and participating in activities for people with dementia:

1. Focus on the person’s ability, not their loss or limitations.
2. Keep activities safe.
3. Use the KISS method: **Keep It Simple** and **Simplify** the instructions.
4. Help the person be as independent as he or she can be.
5. Consider the environment — is it conducive for the activity?
6. Plan familiar activities.
7. Mental stimulation is best in the mornings. Calming activities are best done in the late afternoon or evening.
8. Attention spans are generally short — you will need many activities in one day. Sometimes only one or two steps in a complicated activity may be enough. For example, if a person loved cooking or meal preparation, include them in the activity even if it is only setting the salad bowls on the table.
9. Provide encouragement along the way.
10. BE PATIENT.

If your loved one seems to have lost interest in activity, first assess the situation and try to determine why. Then, review the suggestions listed in this article. You may find that these suggestions in combination with a little praise and encouragement will make a difference. If, however, you have tried to engage someone with dementia in activities and you are sure he or she is not responding, a call to the doctor is always appropriate. Depression may be involved and it is very treatable.

Activity ideas are available at the Chapter office Family Resource Center or call the office at (913) 831-3888 and ask for a copy of the Activity Idea Sheet. 

## Northwest Missouri Regional Office and Area Agency on Aging Encourage Safe Medication Management

People with Alzheimer's aren't the only ones who forget. Sometimes busy and stressed caregivers forget, too. They may even forget important things like dispersing certain medications at specific times.


In order to help caregivers manage their loved ones' medication more effectively, the Northwestern Missouri Regional Office partnered with the Northwest Missouri Area Agency on Aging to provide automatic pill dispensers and education materials.

The Northwest Missouri Area Agency on Aging provides MedGlider automatic pill dispensers free of charge to people age 60 and older who live in one of the 18 counties of Northwest Missouri. The device can be programmed to remind caregivers when to disperse medication to their loved one. An alarm sounds and continues until the medication is removed from the device. MedGliders contain up to one week's worth of medication.

According to the National Council on the Aging, 25 percent of all prescription medications are consumed by people age 65 and older, and of those people, one in five requires help managing their medication.

Through the Northwestern Missouri Regional Office, caregivers of patients 60 years and older can have a MedGlider automatic pill dispenser mailed to them, as well as literature about medication management and potential drug interactions.

The MedGlider system should not be used as a medication safety device – it's designed as a reminder and management system.

If you live in Northwest Missouri and care for a loved one age 60 or older who takes prescription medication, please contact the Northwestern Missouri Regional Office at 816-364-4467. 

## High School Boy Builds Activity Boards in Pursuit of Eagle Scout Ranking

Jon Mayotte, a senior at Liberty High School, was searching for just the right project to complete his Eagle Scout rank with scout troop #374. A woman at his church mentioned to him how her husband was cared for at a local facility for those with dementia and how he enjoyed working with the "activity board." The board had several components, all which help his motor skills and hand-eye coordination. The only problem was that the facility only had one board and several residents who enjoyed using it.




*Jon Mayotte built 12 activity boards for dementia patients while in pursuit of his Eagle Scout ranking.*

Jon knew immediately that he could help. More boards were needed and he needed an Eagle Scout project, so he went to work.

Jon spent more than 80 hours cutting, grouting, routing, sanding, staining and adding the implements. His uncle advised him with the cutting and his mother assisted him with staining. His mother said, "There is so much dedication necessary for this Eagle accomplishment. We are very proud of him."

On his 18th birthday, Jon added the final touches and delivered 12 activity boards to the Alzheimer's Association to be given to facilities.

Jon is not only an Eagle Scout, but holds a part-time job and plays tennis for his high school. He is considering attending college at either Northwestern Missouri or UMKC and wants to study international studies and business. With his college aspirations and his compassion for others, we have no doubt Jon will succeed in this world. We thank you, Jon, and wish you the best of luck. 

## Serving Others — It Just Comes Naturally for Some

*I don't know what your destiny will be, but one thing I do know: The only ones among you who will be really happy are those who have sought and found how to serve.*

*Albert Schweitzer*

Terry Smith and Roberta Wiedenmann have a passion for serving others. There is not a paycheck at the end of a day of volunteering — not even an official pat on the back. But they continue to serve, and serve, and serve. It is with great admiration that we introduce you to these amazing volunteers and their stories...

**TERRY SMITH** volunteers through an organization called KC Cares. Terry lost both his mother and sister to cancer and began helping with the Cancer Society. Through KC Cares he saw the many volunteer needs in this community. Terry has helped in many



*Terry Smith*

capacities with the Alzheimer's Association Tivol Golf Classic and Memory Walk, our largest fundraisers. There has never been a task we have asked him to do that he couldn't, and wouldn't, carry out.

Terry is not your ordinary volunteer. Despite working 50 to 60 hour weeks at his job as Operations Manager at Lift Truck Sales and Services, he manages to volunteer between 300 and 400 hours each year with various organizations through KC Cares. During Memory Walk 2003, Terry passed up tickets to two main events in Kansas City so that he could fulfill his volunteer commitment he had made with the Alzheimer's Association.

Terry says he has been blessed in his life and it feels good to give back to others. Terry is a single father with two adult sons. During his spare time he enjoys building stained glass windows and lamps, and taking an occasional ride on his Harley Davidson motorcycle.


### **ROBERTA WIEDENMANN**

knows what it takes to keep a Chapter office running smoothly. Six years ago, after reading a plea for volunteer help in the Chapter newsletter, Roberta offered to serve. She helps to maintain the mailing database among other things one day a week. Her mother died from Alzheimer's in 1992 after an 8-year battle. Since volunteering at the office, she feels that she has more of an understanding of the disease and has found how helpful and informative the Association really is.



*Roberta Wiedenmann*

Roberta worked for Amoco Oil for 23 years, then Sprint for 6-years as an administrative assistant. She is retired and has 2 sons and 2 grandchildren and loves to travel with her sisters in their travel trailer.

The Alzheimer's Association is very thankful for these two dedicated volunteers. Their commitment is more than admirable. It is a privilege to work with them both and it is our hope they find happiness in all they do. 

## VOLUNTEER OPPORTUNITIES

**The Topeka Regional Office** is revitalizing committees to enhance public policy advocacy and fundraising. Contact Jennifer Haller at 800-733-1981 or 785-234-2523 or e-mail [Jennifer.Haller@alz.org](mailto:Jennifer.Haller@alz.org)

**Memories in the Making**® — Volunteer artists needed. See related article on page 12.


**Main Office** — General office volunteers are always needed. Contact Kim Stein at 913-831-3888.

## November Proclaimed as Caregiver Awareness Month by Governor Sebelius

Kansas Governor, Kathleen Sebelius, signed an official proclamation on October 28th designating November as Caregiver Awareness Month. Representatives from the Kansas Department on Aging, the Alzheimer's Association – Heart of America Chapter, and the Prairie Band of Potawatomie were invited to witness the signing.

Prior to giving the proclamation her official signature, Governor Sebelius commented on the vital services provided by family caregivers. She noted how their dedication and loyalty eased the burden of the state and are especially important at a time when the demand for home and community-based services is overwhelming.

The Heart of America Chapter is fully aware of the valuable care provided by family members when a loved one is diagnosed with Alzheimer's disease. More than 7 out of 10 people with Alzheimer's live at home and almost 75% of the care is provided by family members. The remainder is "paid" care costing an average of \$12,500 per year and most expenses are paid out-of-pocket by the family.

We concur with the final statement of the proclamation: "WHEREAS, It is important to recognize the unique and valuable role caregivers play in the lives of others and to urge all citizens to participate in caregiver awareness activities." 



*Governor Kathleen Sebelius is joined by Secretary on Aging, Pamela Betts-Johnson, and Heart of America Program Coordinator Jennifer Haller following the signing of the Caregiver Awareness Month Proclamation.*

### Important Dates on the Horizon

**APRIL 24**  
Caring for the Caregiver

**MAY 1**  
Safe Return Mayday

**JUNE 13 – 14**  
Tivol Golf Classic

## Memories in the Making<sup>®</sup> Artists Need Your Help

Memories in the Making<sup>®</sup>, an art therapy program for people with dementia, sponsored by the Alzheimer's Association – Heart of America Chapter, is becoming popular in many facilities across the Chapter's bi-state service area. This growth is exciting, but with growth comes the need for additional volunteers to facilitate the sessions.



Each facility has a staff member who attends the art sessions. A trained volunteer facilitator attends as well. The program is in need of volunteers for these facilitator positions. Volunteers do not need to be professional artists. Only a love for art and compassion for the elderly is required. If you can dedicate one hour per week on a consistent basis, then we would like to hear from you.

Volunteers are especially needed in the Lee's Summit and Independence, MO areas and Topeka and Lawrence, KS areas. For more information, or to volunteer, please call Kim Stein at the main chapter office, 913-831-3888.



## Defining Hope

The third annual Defining Hope lecture highlighting new medication and research on the horizon in the field of Alzheimer's disease was held November 7th at John Knox Village. John C. Morris, M.D. was the guest lecturer. Dr. Morris, the Harvey A. and Dorismae Hacker Friedman Professor of Neurology and professor of Pathology and Immunology at Washington University, St. Louis, is Director of the Center for Aging, the Memory and Aging Project and the Memory Diagnostic Center and is Principal Investigator of the Alzheimer's Disease Research Center at the same institution.

Dr. Morris reviewed research directions in the study of Alzheimer's disease and discussed new medications being studied to treat the disease.

Thank you to these sponsors who support the Conferences of Hope:

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## Topeka Change of Postal Address

As of January 1, 2004, the only address that the **Topeka Regional Office** will accept mail at is:

Alzheimer's Association –  
Heart of America Chapter  
Topeka Regional Office  
515 South Kansas Avenue, Suite B-2  
Topeka, Kansas 66603

The post office box previously used will not be available after that time.



*John C. Morris, M.D. spoke to professionals and caregivers at Defining Hope, the Alzheimer's Association - Heart of America Chapter's third annual lecture highlighting new medication and research on the horizon in the field of Alzheimer's disease.*

## Person to Person Support Program Connects Caregivers

A friend reaching out to friends is the motivation behind the Northwestern Missouri Regional Office's Person-to-Person Support Program.

While support groups provide comfort, understanding and advice, some caregivers are unable to attend monthly meetings due to work, and others live in rural areas and may have to travel long distances in order to attend.

Now the benefits of a support group are just a telephone call away. The Person-to-Person Support Program connects Alzheimer's caregivers who cannot attend traditional meetings with volunteers who also have experience coping with Alzheimer's disease. Volunteers call caregivers on a monthly basis to keep updated on their situation, offer advice and provide a caring ear to listen.

Listening and relating are the primary goals for the program. Volunteers must have experience with Alzheimer's disease so they can better understand the emotional, physical and mental strain faced by Alzheimer's caregivers and family members.

Caring for a loved one with Alzheimer's disease can be a very isolating situation, especially for rural caregivers without many available resources. The Person-to-Person Support Program helps destroy the support and communication barriers that exist for these rural caregivers by providing the opportunity to speak and share with someone who understands the challenges of caring for a loved one with Alzheimer's.

Person-to-Person volunteers also provide support in a personal setting — a private telephone conversation — that allows caregivers to talk openly about their emotions, which some may feel uncomfortable about sharing in a group environment.

For more information about the Person-to-Person Support Program or to volunteer, please call 816-364-4467.



## Northwestern Missouri Regional Office on the Road for Education

The Northwestern Missouri Regional Office serves some of the most rural regions of Missouri, including Mercer, Putnam and Worth Counties. These areas also have high percentages of people over age 65. While there may not be a lot of large communities in these remote areas, there is not an absence of Alzheimer's families. In fact, Alzheimer's caregivers in extremely rural locations are more likely than urban caregivers to keep their loved ones at home without outside assistance and less likely to reach out for help.

In an effort to reach out to caregivers, families and professionals in these rural areas, staff from the Northwestern Missouri Regional Office set up routine education visits to each county in their 18-county service region. These visits began in 2003 and will continue throughout 2004. During each visit, staff members meet with representatives from long-term care facilities, home health agencies, hospitals, public administrators, division of senior service agencies, physician offices, church congregations and individual families and caregivers. Staff members deliver education materials, describe training opportunities and provide guidance, support and assistance to professionals and caregivers.

Through these education visits, the Northwestern Missouri Regional Office hopes to increase utilization of Chapter services in the most rural parts of Missouri. Personal contact helps create a relationship between the Association and rural caregivers and encourages communication and outreach.

For more information or to schedule a visit in your area, please call the Heart of America Chapter 24-hour Information and Support Line at 1-800-733-1981.



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## Alzheimer's and Lewy Body Disease — Important Similarities and Differences

On the next page you will read about a very brave man and his family. The man, Mel Garner, has Lewy Body disease, a form of dementia. Although some of the characteristics of both diseases are similar, there are definite differences. The following information explains these differences.

Alzheimer's disease is the most common cause of middle and late life dementia, accounting for 60 to 70 percent of all cases. However, over the last 15 years there has been increasing recognition of another disorder which is now thought to be the second most frequent cause of dementia, Lewy Body disease. Dementia with Lewy bodies is a form of dementia that shares characteristics with both Alzheimer's and Parkinson's diseases.

The early stage symptoms of Lewy Body dementia are quite different from Alzheimer's disease. Lewy Body patients have waxing and waning cognition. Some days they are able to think clearly and go about their daily activities quite normally. Then, in a matter of minutes to hours, they can become acutely confused. Alzheimer patients have good days and bad days, but never have completely normal memory and cognition. When patients have what is sometimes called a "Lewy spell," they may have a "brown-out," where they will be talking and then "space out" and stare into space. One Lewy Body patient described these periods of confusion by saying, "It is like someone is blowing fog into my brain."

Short-term memory in Lewy Body patients is usually quite good, unlike with those who are suffering from Alzheimer's disease. Lewy Body patients often have severe visual-spatial difficulties. For example, a Lewy Body patient may go to the bathroom in a restaurant, get confused and not be able to find the way back to the table. During a Lewy spell, the patient may have difficulty concentrating and completing tasks.

Lewy Body patients share a similar brain pathology with people who have Parkinson's disease. Patients with Lewy Body often move very slowly, have a slight bent-forward posture, and tend to shuffle. They are at risk for falls because they do not have a good "righting reflex" if they trip on something or are jostled in a crowd. Unlike some Parkinson's patients, people with Lewy Body do not usually have a tremor.

Between 50 and 80 percent of all patients with Lewy Body dementia have visual or auditory hallucinations early in their disease. Lewy Body patients often report seeing little people or children sitting on their couch or small animals running around the home. Sometimes Lewy Body patients will have phone conversations when there is no one on the line or will have conversations with photos of their loved ones. The Lewy Body patient may become very upset and agitated if family members argue with them about the reality of their visions. Caregivers often find it helpful to state, "I can't see the children sitting on the couch, but I believe you do see them."

Treatments for Alzheimer's disease, such as Aricept, Exelon, and Reminyl, often times can improve Lewy Body dementia symptoms significantly. With treatment, many patients have a lessening of the frequency of Lewy spells, a greater ability to concentrate and a decrease in hallucinations.

It is very important for patients to receive the diagnosis of what type of dementia they are suffering from, so that they may be treated with the appropriate medication. In addition, caregivers can help their loved ones more effectively when they understand the diagnosis and cognitive impairments with which their loved one is grappling. Focusing on cognitive strengths and de-emphasizing deficits allows the Lewy Body patient to enjoy a better quality of life.



## Rural Kansas Family Committed to Each Other

Cheryl, Mel and Lindsey Garner of rural Fairview, Kansas know what is truly important in life. Without hesitation they will tell you that “love not only continues but survives and even deepens through difficulty.” They share these thoughts through the way they talk, smile at each other, laugh and cry at knowing what is ahead.

In the fall of 2000 Mel started to experience short periods of dementia symptoms. These included misnaming familiar foods and the inability to complete familiar tasks. He also had physical symptoms of muscle jerking and chest pain. Finding the correct diagnosis for these symptoms proved to be a frustration for both Mel and Cheryl, his wife of 17 years. It was only after many tests and being misdiagnosed that they were finally referred to the Mayo Clinic in Minnesota where a diagnosis of Lewy Body was made.

Lewy Body dementia is very similar to Alzheimer’s disease with progressive loss of memory, language, calculation and reasoning as well as other higher mental functions. However the progress of the illness may be more rapid than seen in Alzheimer’s disease (see related article on page 14).

One of the unique symptoms of this type of dementia is the fluctuations in confusion which Mel does experience. Cheryl shares that these acute episodes of confusion can vary hour to hour or even day to day, intertwined with periods of being oriented and lucid. She says that with these fluctuations they have learned not to have expectations, and then they won’t be

### Heroes of the illness



*Cheryl, Mel and Lindsey  
Garner*

*The actual dementia physically affects only Mel, but his entire family, Cheryl and Lindsey, rally with Mel every day to ward off the challenges that this disease bears.*

*Their support for Mel in his illness is admirable. The way they inspire one another is remarkable. The commitment that they have made to each other is everlasting.*


disappointed when plans need to change.

Mel says his daughter Lindsey, age 15, is an inspiration to him. He spoke of how she has successfully coped with her juvenile diabetes for five years and is wise beyond her years. Lindsey says she feels so fortunate to have a father and “mom is always there to help me.”

Mel shares that one of the most difficult results of this disease is not being able to financially provide for his family. However he has found a way to give back to the community. Weekly, he shares his sense of humor and good nature when he visits a local nursing home. He plays his guitar, sings for the residents and

tells jokes. Mel says the residents give him lots of love, right from their hearts as they are all touched by his musical talent.

The Garners have experienced a huge outpouring of support from family, friends and the rural community extending from Fairview to Sabetha and Hiawatha. The local first responders have also been supportive and responsive. They have initiated county wide searches on four separate occasions when Mel wandered. One time he traveled seven miles by foot. Cheryl has firsthand experience of the positive outcomes of having Mel registered in the Safe Return program.

So what is the glue that holds this family together in spite of the challenges of this disease? Mel says his number one mission in life is to just love Cheryl and Lindsey harder today and let the future take care of itself. 



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