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Midlands Chapter selected to present at nationwide Alzheimer's conference

by Nichole Baugh

The Midlands Chapter Alzheimer's Association was among the 10 percent chosen to present at the 2010 International Conference on Alzheimer's Disease (ICAD) held this year in Honolulu July 10-15.

ICAD is the world's "largest and most prestigious conventions of Alzheimer's experts." The event brought together 4,000 researchers from around the world to consider ideas, inspire one another, stimulate diverse viewpoints and create opportunities for collaboration, according to Alzheimer's Association ICAD 2010 overview program.

After hearing about the international conference, Diane K. Hendricks, social worker, and Clayton Freeman, program director for the Midlands Chapter, wanted to get involved. They submitted a summary of data collected from Midlands Chapter participants in a U.S. Administration on Aging and Nebraska State Unit on Aging Consumer Directed Demonstration Grant.

The Midlands Chapter was invited to do a poster presentation at the event.

They were "thrilled that the research completed in Nebraska on younger-onset Alzheimer's disease rose to the top of areas to focus on at this international conference," Hendricks said.

The presentation was titled "Awareness, assessment and education: an early stage program to support caregivers of individuals with younger-onset Alzheimer's disease."

Posters were displayed each day with high traffic for discussion, thoughts and ideas.

"Professionally, I had the opportunity to network with individuals across the world," Hendricks said.



The event itself was "well organized and had a variety of choosing each day," Hendricks said. "Each day opened with two featured researchers and then a breakout session, which ran for two hours with various speakers for 15 minutes at a time."

During one of the sessions, The Alzheimer's Association announced the launch of TrialMatch, an interactive tool for people with Alzheimer's, caregivers, families and physicians to "locate clinical trials based on personal criteria (diagnosis, stage of disease) and location," according to the Alzheimer's Association website.

Another session featuring researchers from the University of California, Irvine indicated that exercise can play a positive role in reducing the risks of dementia, Hendricks said.

"Meeting others across the world who are fighting the same fight created an inspiration and renewal of focus to work even harder when returning to our own communities and making a difference knowing we are in this together globally," Hendricks said.

Next year's event will be held in Paris, France, from July 16-21. ■

New bill mandates additional hours of dementia training for care facilities

□ by Kristen Cloyed and Alyssa Roth

Four hours of training specifically in Alzheimer's disease and other forms of dementia are now required for staff members who care for patients in licensed Nebraska care facilities.

LB 849 was signed into law by Gov. Dave Heineman April 13, 2010. The measure amends the Alzheimer's Special Care Disclosure Act by requiring that at least four of the 12 training hours staff members attend focus specifically on dementia.

Clayton Freeman, program director of the Alzheimer's Association's Midlands Chapter, said training hours must focus on caring, communicating and understand patients with dementia. "We believe people with dementia should be given the highest quality of care," Freeman said.

In Nebraska, 75 percent of the state's 27,000 care facility residents have mild to severe dementia. Many of these patients will require long-term care.

The Alzheimer's Association of Nebraska supported LB 849, which was sponsored by District 32 Sen. Russ Karpisek, who initially introduced LB 726. That was later amended to LB 849, making it part of the Health and Human Services Bill.

For Jane Prochaska, who testified for the bill before Nebraska's Health and Human Services Committee, the bill was personal. Prochaska's mother, who has since passed away, suffered from vascular dementia.

"Even though she's gone," Prochaska said, "It's still important to me."

As a former judge, Prochaska worked in probate law for 20 years, so she was no stranger to the legal system. However, Prochaska described her time on the bench as "boring."

Before Prochaska became a judge, she worked for 10 years as a lawyer for dementia patients, serving as personal guardian for many of her clients. She always knew she wanted to work with the elderly again. A sudden event set Prochaska's plans in motion.

Though everyone remembers the terrorist attacks on Sept. 11, 2001, Prochaska remembers that day for more personal reasons.

"I'll never forget that day," she said. "I got a call from my mother at 4 in the morning. As I talked to her, I could

tell something was wrong."

Prochaska hurried to her mother's side. When she found her mother sitting alone in her dark living room, Prochaska sought help.

"She said she had been sitting there for three days because she was dizzy and she had been crawling to the bathroom," Prochaska said.

Prochaska took her mother to the Nebraska Medical Center, where doctors explained her mother had a stroke, leaving her with vascular dementia. Later, Prochaska realized warning signs had literally been posted around her mother's house.

"She'd have 50 to 100 sticky notes in her kitchen," Prochaska said. "The notes said things like 'get the mail' or

□ **"We believe people with dementia should be given the highest quality of care."**

-Clayton Freeman

□ **'take out the trash' - things she wouldn't normally forget."** She also noticed some of the words on the notes were misspelled, which was unusual because her mother was "a very good speller."

After her mother's diagnosis, Prochaska started thinking about opening her own care facility. Many of the places she visited left her with a bad impression. Prochaska noticed a need for care facilities that specifically catered to patients with dementia.

"A lot of the places locked them all in a dead-end hallway with two big steel doors that slammed shut. The nurse's station wasn't even in with the patients," she said. "It was outside of those steel doors. All that was inside was a couple of teenage aides who had no clue what they were doing."

Though most patients could walk, Prochaska noticed many facilities put patients in wheelchairs because the patients were easier to move.

"They would park them in their rooms and let them sit there alone," she said. Her passion *(Continued on page 3)*

NEW BILL MANDATES ADDITIONAL HOURS

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as she testified helped the bill become a law.

"Having been through that with my mother, I asked myself 'How can I, as a judge, do more?'" Prochaska said. "I was testifying as a family member who has seen someone go through this and as a business owner who has hired staff and had to train them."

In 2007, Prochaska opened Silver Memories, a residential care facility that provides assisted living for individuals with Alzheimer's disease, memory loss and other forms of dementia. Prochaska said she brings in specialists to train her staff.

"Almost all the training we do is on dementia," she said. The focus on dementia is important, Prochaska said,

because there are always new ideas and new medicines being introduced. Training is important for everyone, whether they're a new employee or a 20-year veteran.

"You want to keep them current, as well as train the new people coming in," she said.

Prochaska stressed that this new law should not be an additional burden. Care facilities already require 10 to 12 hours of training.

"The only thing that's different is that now part of that training must be with dementia," she said. "It should make the management a little more conscientious and a little more aware that four hours need to be about dementia." ■

Daughter witnesses mother, grandmother struggle with Alzheimer's

□ by Tiffany Price

Editor's note: When Tiffany Price enrolled in the spring News Editing class, little did she know that her own experiences would parallel what she'd be doing in class. Price watched her mother, Fiona Hutches, make the difficult decision to place Price's grandmother in an assisted living facility. Price recounts her own emotions as she watched two women she loves come to terms with the disease.

Days go by before you realize that you need "me time." Taking care of a loved one with Alzheimer's disease is not easy, but someone has to do it. And for the primary caregiver, "me time" becomes a precious commodity that's often last on your list of priorities.

When is it time to decide whether you, as a caretaker, can no longer do it? For our family, this decision was stressful and emotionally draining.

"I was feeling so guilty about even having to make this decision in the first place," Fiona Hutches, my mother, said. "I was at the point of a nervous breakdown before I realized I couldn't do this anymore."

Hutches was a full-time worker and caretaker of my grandmother for the past year. During that time, my mother suffered what many call mini-strokes. Two put her

in the hospital, but even then her feelings of guilt made it hard for her realize it was time to do something else for my grandmother.

Now, Hutches is realizing that the decision to move her mother into a care facility this past spring was the right one for her and her family.

"I wanted to do it on my own, because it is my mother," Hutches said. "I even left her bedroom exactly the way she left it, just in case she wanted to come home.

"Now I know that this is the best thing for my mother."

Hutches said that everyone is at peace. No one is stressing about who's going to watch grandma or who'll feed her. Wondering where "me time" went isn't an issue.

I was engulfed in the stress of helping my mother on a regular basis. At 22, it started to affect my personal life, as well as my studies at school. I only spent a small percentage of the time my mom spent caring for my grandmother. Because of the stress I was feeling, I knew that my mother had it 10 times worse.

After realizing how desperate my mother sounded each time she needed help with my grandmother, I told her that we needed to figure something else out.

"I wasn't getting 'me time,'" Hutches said. I absolutely agreed and knew that it was un- (Continued on page 4)

MOTHER AND GRANDMOTHER STRUGGLE

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healthy for my mother, especially after her mini-strokes. We looked into several places before finding a place that my grandmother liked.

My grandmother now lives in a small house that cares for only women who have Alzheimer's, young-onset Alzheimer's and other dementias. She is happy and content with the place she calls "home" now. It's

her own place and she smiles with joy because it makes her feel independent.

"I no longer feel guilty, after seeing the smile on her face every time I go to see her," my mother finally told me. And I no longer feel the stress of balancing school and work with concern for my mother and caring for my grandmother. ■

Expressing memories through watercolor

by Dani Grant, Rayna Fleming and Shannon Stawniak

You can't speak. You have a lifetime of memories to share, but you lack the communicative ability to express your thoughts, wishes or needs. It's frustrating. How do you share your stories with the people around you?

Art may be the answer.

Memories in the Making, created in 1986, is a program designed to open pathways of communication between a person with Alzheimer's disease and his or her caregivers, families and friends. By creating watercolor pictures, people with Alzheimer's can recreate and share images locked in their minds. The program is meant to increase social interaction for patients and caregivers, allow patients to reminisce and provide a creative outlet for patients.

Dr. Andrea Thinnies, an occupational therapist and assistant professor at Creighton University, recently conducted a study to look at a different aspect of the program. She wanted to understand how Memories in the Making could also benefit caregivers, family and friends of those with Alzheimer's disease. Thinnies analyzed the stress levels of caregivers before and after the six-week program.

Thinnies said that any activity that a caregiver and a person with Alzheimer's disease can share "can be beneficial," and hoped to see caregivers experience lower stress levels during the program because painting can be tranquil.

The subjects of the study were caregivers who had a person with Alzheimer's living in their home. Thinnies conducted six sessions of Memories in the Making with 18 caregivers divided into three groups.

In two groups, the caregivers actively participated in the Memories in the Making program by painting with the people with Alzheimer's. The third group served as a control group and only included the people with Alzheimer's

disease without their caregivers.

Participants were seated around tables with minimal distractions and Thinnies provided other works for inspiration. Participants could create a new painting each session or continue to perfect the same work throughout the program.

"This is not an art class," said Thinnies, who became involved with Memories in the Making in 2006 as the first and only occupational therapist in the nation trained in the program, "rather an art experience in which people choose what they would like to paint, what colors they would like to use, and what they name their finished piece."

Alzheimer's Associations that are active in the Memories in the Making program ask participants if they would donate their paintings to an art auction that serves as a fundraiser for the association, Thinnies said. However, for the purpose of Thinnies' study, all of the artwork remained in the possession of the participants.

The Alzheimer's Association website described the effects of the program: "The artists speak with powerful brush strokes of color and tentative tracings of line. They pull us into the world of an individual with Alzheimer's. As we look at their paintings, we see their stories in a language that needs no words. Their paintings show us glimpses of who they were and who they still are." ■



Take two jokes and call me in the morning

by Jen Czuba, Jacinda Drakulich and Sara Jo Smith

Watching the blooper reel on a DVD is sometimes the best part of renting a movie. Seeing people snicker and giggle and experience hearty belly laughs is one of life's high points.

Laughter just makes people feel better. Some researchers can explain why, while others just believe in laughter's healing effects. Either way, encouraging laughter can do no harm.

It's easier to think about birthday parties and beautiful days in the park with a smile on your face rather than facing everyday trying moments. Caretakers and those with Alzheimer's really only have two options: wallow in the sorrow or laugh in the face of negativity. Author Kurt Vonnegut once said: "Laughter and tears are both responses to frustration and exhaustion. I myself prefer to laugh, since there is less cleaning up to do afterward." Humor takes away the fear because it changes your perspective on what has happened and what it is going on now.

"Laughter and tears are both responses to frustration and exhaustion. I myself prefer to laugh, since there is less cleaning up to do afterwards."
-Kurt Vonnegut

Laughter separates you from the situation and gives you a way to get through life's little mishaps. "Amongst us caregivers, we have to make light of it because it helps us with coping," Diane K. Hendricks, social worker, said. So when keys are put in the sugar bowl or a jar of mayonnaise is out on the counter and you can't remember why, a smile may relieve the anxiety.

Trish Tuel, who has young on-set Alzheimer's, has learned that laughing is important to get through the day-to-day trials, and she enjoys the life she's leading. "I don't want to hold myself back because of this," Tuel said. "I'm going to enjoy life as much as I can before I go."

Even through tough times, Tuel and her best friend and caregiver Judy Osstransky make every day better by laughing through it. "We laugh. We have a good time," Osstransky

said. "It's really funny when both of us can't remember."

In addition to lightening the moment, laughing just plain feels good. And everyone has heard how relaxing yoga is. Now, one doctor from Mumbai put the two together to create a complete well-being routine.

"Laughter Yoga plays an important role in helping people suffering with Dementia and Alzheimer's disease," Dr. Madan Kataria, co-founder of Laughter Yoga International said on his website. "It is ideally suited for such people because they cannot comprehend humor, due to lack of cognitive abilities."

Because Laughter Yoga (www.laughteryoga.org) brings in physical exercises that improve bodily functions, it brings the same good things to the body that exercise does. Kataria said that Laughter Yoga helps increase oxygen to the brain cells, which improves brain functions, and also releases certain chemicals from the brain, helping lift depression.

"If it (humor) is a part of their family of origin, in terms of using humor to cope and make light of things, I think it will be useful at any stage," Hendricks said. "Even in the non-verbal stages, you can still tell they appreciate the humor."

One of the most memorable sounds in life is a child's laugh. Advertisers have even found that the sound of an infant's laughter connects with a large audience. A simple little laugh can bring a smile to anyone's face. Share a joke in group. When you're having dinner, talk about something silly that happened during the day. Laughing together creates bonds and strengthens relationships.

Hendricks said that timing is important and that relationship history makes a big difference as to whether humor is appropriate. "They are the ones who set the pace for us."

Humor is a language all its own and serves as a way to discuss difficult topics. It lightens the situation and makes people feel more comfortable, which invites more open communication.

Getting a patient to engage with you can be a difficult task. Allow humor to lead the engagement. Even though people may have lost their cognitive ability to understand, they can still appreciate a smile or laugh.

Nurse Sue Smith, assistant professor of Nursing at Iowa Western Community College, (*Continued on page 6*)

TAKE TWO JOKES AND CALL ME IN THE MORNING

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said: "Joking around with our patients helps to build a trusting environment with them. It is helpful to build relationships and bond with patients, as well as lighten the mood to improve communication."

Smith also instructs her nursing students to assess the audience. "Some people do not want to joke around, but for others it helps relieve the anxiety of a very stressful situation," Smith said. She added that as a nurse and care-

giver, it is important for her to laugh because of how emotionally taxing the job can be.

"Laughter gives a distance," Bob Newhart, Golden Globe winning actor, said. "It allows us to step back from an event, deal with it and then move on." Frustration, anxiety and depression are some of the negative emotions caregivers experience. Alzheimer's patients feel the same thing. The ability to laugh can overcome a number of obstacles. ■

Alzheimer's can't slow couple's adventurous spirit

by Jessica Leisure, Ainslee Kardisco and Kirby Kaufman

Allan and Sharon Schur have been a lot of places.

The retired Bellevue couple visited a former exchange student in Germany. Last August, they saw glaciers during an Alaskan cruise.

But travel for the two hasn't been quite the same recently. In 2005, Sharon, 59, was diagnosed with Alzheimer's disease. Her 60-year-old husband said the disease is like an avalanche.

"For a while you're able to slow down the snow, but it'll get around you," Allan said.

Sharon is progressing through the stages of the disease, but travel is still manageable, Allan said.

The couple married after Allan joined the Navy. Allan was a lieutenant colonel and his wife was a nurse. They moved to numerous places while Allan was in the military. They worked together as a team, and life became more about the "we's" and not the "I's."

It's the same philosophy now.

In March, the couple traveled to Washington, D.C., where they attended an Alzheimer's forum. Those who attended the event spoke with state congress members about Alzheimer's legislature. For Allan and Sharon, the day involved sharing their stories with key lawmakers, as well as sharing plenty of time on foot.

"It was exhausting and exhilarating," Allan said. "I felt like we were getting something done."

Last fall the Massachusetts natives visited a former Air Force base near Marquette, Mich., where they saw one of their old homes. The home showed wear, its windows covered by plywood.

"It was so sad," Sharon said.

When the couple isn't traveling, they are taking part in



(Left to right) Sharon and Allan Schur visit with Clayton Freeman, program director of the Alzheimer's Association of the Midlands Chapter, during Volunteer Appreciation Night.

a clinical trial at the University of Nebraska Medical Center. The trial was double blind, so the couple and their doctor didn't know whether Sharon received a placebo or the actual drug, Bapineuzumab. The drug is designed to reduce or eliminate plaque buildup in the brain that researchers have linked to Alzheimer's.

"It's something that people with Alzheimer's can do to help research," Allan said. "But it may not help them."

Alzheimer's is difficult, Allan said, but consistency makes things a lot easier.

For the time being, Sharon will conclude her drug trial. In fact, Allan made a video documenting her journey through the trial. They'll also continue their journey in a more literal sense.

Allan and Sharon's next destinations: New England and Colorado Springs. ■

Planning ahead prevents awkward situations

by Chase Spenser

Tom Hurst still wants to go out. It's just that for him and his family, public and often busy places have become more difficult for the 67-year-old to handle with Alzheimer's disease.

Though Debra Peters doesn't suffer from Alzheimer's, she is familiar with these situations.

"When we go into stores, restaurants, or most public venues, there is always a little awkwardness," said Peters, who cares for her 74-year-old mother. "I can feel the looks and the second glances, it's almost like people have never seen a disability before."

Kristin Donovan, who helps care for her stepfather Hurst, has experienced her share of awkward moments in public, too. The noise in public places, like crowded restaurants, is a problem for him, Donovan said.

"We try to anticipate what he needs, and we try to keep him out of awkward situations. But that doesn't always work."

- Kristin Donovan

Hurst can't order for himself anymore, either. Fortunately, the family is good at remembering what he likes at each restaurant.

"We try to anticipate what he will need, and we try to keep him out of those (awkward) situations," Donovan said. "But that doesn't always work."

Being prepared is something that Diane Hendricks, a social worker with the Alzheimer's Midlands Chapter and the UNMC geriatrics department, also said is key.

"It is important for caregivers to anticipate the environment and prepare for situations to occur," Hendricks said. "It's easier to redirect the situation when you are prepared for it."

Unfortunately, caregivers and those they are caring for are victims of public ignorance and unintentional embarrassment and awkwardness. Because of the immensely different behaviors those with Alzheimer's can have, the public doesn't always react appropriately.

An awkward situation may cause a person to lose his or her temper, sarcastically mutter back or any number of things. Hendricks said there is "no real right answer" for smoothing out those uneasy moments.

"The key is to lighten up the situation and put it in perspective," Hendricks said. "As a caregiver you need to decide if it's worth the battle."

Hendricks said there are several things that caregivers can do to help smooth over awkward public situations. Sometimes all it takes is a simple apology, or a backhanded apology. Thanks for understanding and being so patient, or 'You know, her memory isn't what it used to be,' works effectively," Hendricks said.

One new trend that caregivers are turning toward is something that resembles a business card. The card can be given to servers, cashiers or anyone who may be in contact with the caregiver's loved one. The cards say something along the lines of, "Thank you for understanding, my loved one has memory problems."

"This technique has become popular because caregivers are able to let people know that their loved one has memory loss, while keeping their dignity," Hendricks said. "These cards can be easily passed to people after an awkward exchange without making a bigger deal than it needs to be."

Humor is a valuable coping mechanism, one that many people like Donovan and her family already practice.

While she was at work, she got a phone call from her stepbrother asking, "What was that kind of beer dad likes?"

She said it was a little embarrassing having to answer "Irish red" and wondering what work her coworkers thought the phone call was about. Afterward, Donovan said it was kind of funny.

"If humor has been used in the family as a coping mechanism, then humor is an appropriate solution," Hendricks said. "Each family is accustomed to their own way of dealing with things, and it is important not to stray away from your own family values." ■

If you have any questions or comments about this edition of "News & Views" please feel free to contact Nichole Baugh at nchlmarie@gmail.com.

Thank you for reading!