

"News and Views" is a quarterly, online publication for caregivers, families and individuals with young-onset Alzheimer's disease and other dementias. Students from the University of Nebraska at Omaha's School of Communication, Fine Arts and Media wrote and edited the publication in conjunction with the Alzheimer's Association Midlands Chapter.

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Speak to me...learning new techniques can help Family and friends communicate with loved ones

by Emily Hough, Courtnei Kopietz and Laura Winingham

Life changed for Patrick Bartmess and his mother, Dr. Janet French, in 2007 when French was diagnosed with young-onset Alzheimer's disease. Bartmess had just received his bachelor's degree in education from the University of Nebraska at Omaha. He was able to substitute teach for about a year before he decided to stay home full time and care for his mother. Mother and son shared an interest in teaching – Janet was a speech professor at College of St. Mary and UNO.

Patrick believes that Janet's verbal and social skills are still intact because of her profession as a speech teacher.

"Those are the skills that are sticking with her. It's the memory that's the problem."

Patrick said his mother will see the time on the digital clock, but she won't know what day it is until she goes out to get the paper. He also said Janet repeats conversations they've already had. While most people would feel defensive when repetitive conversations are pointed out, Patrick said he thinks it is important for Janet to know that it is something they have already discussed. It is a struggle to find a balance in tone and communication.

Janet and Patrick are not alone in their struggle with communication. Mike Majeski and his wife and caregiver, Kathy, also have difficulties when it comes to communicating. Kathy said Mike will begin a sentence and she will finish the thought for him, though this was something they were able to do before Mike's diagnosis.

"We're together a lot and we just always knew what each other was talking about. If we're on a topic and just talking along, I



pretty much know where he's going with the thought. When it's something out of the blue, it's a bit harder."

Kathy said that she needs to be patient and sometimes their conversations turn into a guessing game.

Karen Anderson, a speech-language pathologist at Methodist hospital, said: "For a person with any type of dementia, non-verbal comprehension of body language, vocal tone and facial cues will stay intact for a long time." Nonverbal communication can help family and friends develop more effective conversation.

When it comes to having guests, especially during holidays and family celebrations, a few steps can ease communication. Caregivers can help by bringing out photographs a few days or weeks

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Reminder

✓ Check your e-mail for the monthly informal meetings at Panera Bread.



Faith, love help couple cope with Alzheimer's

by Sara Benson, Adam Hrabik and Amanda Meyers

Her body trembled a little, anticipating the words she so badly wanted to share. Her eyes filled with tears. Only the comforting touch of her husband's hand slipping into hers provided reassurance, encouraging her to fight for the words. Her determination paid off as she softly said, "I didn't know what was happening to me." It was a short sentence, just eight words, but Liz Johnson's determination and spirit were evident in the 60 seconds it took her to utter that sentence.

Liz was diagnosed with young-onset Alzheimer's disease in 2007. Daughter Michelle first noticed changes in her mother's behavior; however, the family attributed Liz's episodes of confusion to the stresses of daily life. Terry, her husband of 35 years, remembers the day she struggled through a game of eight ball with her brother. After Liz's inability to connect her thoughts to her actions during that pool game, Terry decided it was time to for medical intervention.

Symptoms of Alzheimer's disease vary with each individual. Terry said Liz struggles expressing the ideas and thoughts she develops in her mind. Liz also experiences restless leg syndrome, which can be a complication associated with the disease. Alzheimer's has softened her voice, but not claimed her spirit. "She still has her sense of humor," Terry said.

Even before the diagnosis, the Johnsons shared a passion for learning, which was manifested in Liz's life through music. She spent many years dedicated to the Kindermusik

program, teaching children up to 7 years old music lessons. While she is no longer able to teach music, it is not uncommon for her to give some attention to the beautiful piano in the couple's home.

Terry, a professor at Grace University, teaches evening classes once or twice a week. The disease has had an effect not only on Liz's career, but his as well. Time constraints have resulted in reducing the number of classes Terry can teach, which in turn reduces the couple's income. In addition to his professional responsibilities, Terry also teaches preparatory classes to people adding foster or adoptive children to their families.

Shortly after Liz's diagnosis, the couple decided to pursue some lifelong dreams while time was on their side. In 2009, the Johnsons traveled to Israel and followed the trail of Moses and the Israelites. Terry said it was important to both of them to enjoy this experience together while Liz was well enough to appreciate it. They also made a political impact by attending an Alzheimer's conference in Washington, D.C., several years ago where they met with congressional representatives to discuss the disease.

Today, Liz's disease has progressed



Liz (far right) and Terry Johnson cut the ribbon at the beginning of the 2010 Memory Walk with board chairman Larry Guenther (left)

to a point where she needs assistance with all her daily activities. Terry helps with many of these, but the Johnsons are grateful for the assistance of church members who share their time with the couple.

Roles have changed, too. "She used to cook all the meals. She was an excellent cook," Terry said. Now Terry serves as head chef, but Liz enjoys helping when she can.

The disease continues to make an impact on the Johnson family. As Liz's symptoms gradually worsen, the family makes the necessary adjustments. One thing is obvious: they couldn't do without their faith. Liz and Terry agreed that despite all the negative aspects of the disease, it has brought them closer and given them more time with each other.

"There is no over or under, you have to go straight through it," Terry said as he looked at his wife. "We're going to get through it."

Communication skills encourage conversation

Continued from page 1

by Emily Hough, Courtni Kopietz and Laura Winingham

before an event and reviewing relationships, as well as key memories to help make connections. Anderson emphasized that visits from friends and relatives should be scheduled with just a few people at a time because it takes a great deal of cognitive energy to maintain the focus that many social situations demand. Don't be hesitant to rehearse the situation before, coming up with a game plan for the proposed visit.

Guests can follow conversational tips, too. Anderson said it's important to keep the situation relaxed and comfortable and not be patronizing — facial and volume cues should match feelings. Speaking louder doesn't make anyone understand better. And while it can be beneficial to speak a little slower or give slight pauses between sentences, don't be disrespectful by taking it to the extreme.

"Don't quiz or confront the person because it's like playing to their weakness," Anderson said. Anderson gave the example of "Hi, I'm Karen. I'm your neighbor from across the street. I came to tell you happy holidays." A statement like this doesn't force the patient to remember the name, the relationship or the reason for the visit. It alleviates some of the social tension and prompts more enjoyable interaction. When possible, give concrete and textual cues for holidays and occasions, like bringing a gift for a birthday.

According to "Caregiving Tips for Care of the Alzheimer's Patient" by Cindy Stinson, people must be aware of their own body language when communicating. Arms need to be re-

laxed and casual. Facial expressions need to be accepting and open. Body language needs to be friendly and open for questions. Physical touch should be soft and gentle so a patient isn't overwhelmed. The tone of voice and volume are also important when speaking. Pacing words carefully and articulating clearly keep stress levels down.

Multiple techniques can be used to communicate with someone with

"Don't quiz or confront the person because it's like playing to their weakness."

*-Karen Anderson,
speech pathologist*

Alzheimer's disease, according to the article "Listen with the Ears of Your Heart" by Dorothy Seman. Don't ask open-ended questions, the article advises, and always allow adequate time for an answer. Asking questions with limited choices helps Alzheimer's patients narrow their answers. Give one step at a time when delegating tasks rather than several directions at once. Repeat names and facts several times to make sure the information is retained. Be as literal as possible with the wording. Don't assume that what is being said is obvious, the article continues. Maintain eye contact and use positive physical gestures to encourage conversation.

Technology can play a major role in communicating. An electronic device known as Dynovox helps many families. The portable computer essentially talks for patients using pictures

and words programmed into it. Digital photo frames are helpful because patients are constantly being reminded of people and things they need to remember. A simpler version would be physical photo albums. Even Apple has jumped on board with speech technology. The iPad has an application called Proloquo that mimics the functions of the Dynovox.

Patrick Bartmess uses these technologies to help communicate with his mother. Because Janet can't remember what day it is, Patrick hung a day-clock next to the time clock. Patrick also uses a simple notebook when they must make a decision. He draws diagrams of possible outcomes and notes the details of their conversations. Janet can refer to the notes later, which eliminates the stress of constantly repeating information, Patrick said.

The iPad is a major piece of technology that helps mother and son communicate. Patrick downloaded the software for Proloquo, which allows Patrick to use his iPad just as a person would use the Dynovox.

Technologies and recent studies about communication are making it easier for patients with Alzheimer's, caregivers, family members and friends to understand each other, but communication will always be a challenge when someone has Alzheimer's. Research indicates caregivers must remember and accept this rather than turn a conversation into an argument. Instead, be satisfied with the conversation you can have and the shared experiences you can still enjoy.

Long-term care requires professional planning and help

by Tressa Eckermann, Lauren Koch and Ed Watkins

Caring for someone with Alzheimer's disease can be overwhelming as you manage your loved one's daily activities and adjust to his or her diminished capabilities. Despite the hectic days, one crucial thing can't be overlooked - managing your assets and preparing financially for the future. Information from the online source http://www.alz.org/living_with_alzheimers_financial_matters.asp and the book "The 36-Hour Day" by Nancy L. Mace and Peter V. Rabins were used to prepare this step-by-step plan.



When a family member is unable to care for himself or herself and it becomes increasingly difficult and even unsafe to provide care at home, a care facility or nursing home may be needed. However, good care can be very expensive.

According to the Alzheimer's Disease Research Foundation, the average daily cost of a private room in a nursing home is \$219, which adds up to around \$80,000 per year.

For a person with Alzheimer's disease, the annual cost of in-home care is estimated at \$76,000, including medical expenses and indirect costs such as a caregiver's time and lost wages. The care of an Alzheimer's patient, viewed as custodial care, is not covered by Medicare and most basic health insurance plans until most of your financial resources are depleted. Caregivers may want to consider purchasing long-term care policies for themselves, though. Visit with a financial advisor or insurance agent to make that determination.

STEP 1: Determine your assets

Assets are economic resources. They represent ownership of value that can be converted into cash, although cash itself is considered an asset. Assets include, but aren't limited to, savings and checking accounts at banks, stock certificates, bonds, certificates of deposits, savings bonds, mutual funds, foreign bank accounts and anything inherited, including money, jewelry or furnishings.

Pensions and savings plans through employers are also assets. Jewelry, art work and cars are assets, too. Real estate, whether it's the family home or rental property, is an asset.

If you're having trouble locating a loved one's assets, here are some places to look:

Safe deposit boxes: This may require a court order to open, so first look for a key, a receipt or bill indicating whether your loved one has a box.

Military benefits: If your spouse, sibling or parent was a member of the military, he or she may be eligible for

some kind of military benefits. First look for proof of military service, such as discharge papers, dog tags or old uniforms. Next, contact the military to determine what may be available for your loved one. In some cases, dependents of veterans may be eligible for benefits.

Real estate property: Joint or partial ownership of any of houses, land, businesses and rental property fall under this category. Look for evidence of regular payments into or from a checking account, keys, property tax assessments or fire insurance premiums. Insurance agents may be able to help you.

Wills: Ideally, your loved one has made a will, which should list the assets he or she has. Wills are kept by the attorney and recorded by the courts. Some people keep wills in safe deposit boxes or in a safe place at home.

STEP 2: Estimate the cost of care

Many unanticipated expenses for caring for someone living with Alzheimer's can accrue. Medical supplies, services, drugs, adult day services and in-home care services may financially strain the caregiver.

STEP 3: Explore different financial resources

There are many creative ways to finance the hidden costs and expenses associated with young-onset Alzheimer's. It is important to consider all means available to best plan your long-term financial future. Following these steps can help:

Determine how much your loved one may have invested in retirement benefits and IRAs. Work with a financial advisor to see whether funds can be withdrawn without penalties or tax implications.

Look into any employee-funded retirement plans a loved one may have, such

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Long-term care means understanding finances

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as a 401(k), 403(b), and Keough, a form of IRA.

List all your loved one's assets described in step 1.

Consider applying for government assistance, including Social Security Disability Income, Supplemental Security Income and Medicaid.

If you need someone to stay at home with your loved one while you work or run errands, look into programs provided by the Eastern Nebraska Office on Aging. Also, consider recruiting family members, friends and even church groups to provide companionship for your loved one. Private companies offer a variety of services, too.

Call pharmaceutical companies to ask whether the company is willing to donate or work out a plan for you to receive discounted supplies or drugs.

Apply for respite-care grants which assist paying for costs of in-home care or adult day programs. Visit http://www.alzfdn.org/AFAServices/family_grant.html for more information.

STEP 4: Consider the caregiver's finances and seek assistance

Navigating through financial resources and options is extremely complicated. It may become necessary to meet with a financial advisor during this process, as well as an attorney.

If you're a primary caregiver, planning for your own future is important, too. Financial advisors and attorneys can help. Also, as a primary caregiver, it's important to make sure your loved one will be financially secure if you die first. An attorney can help determine whether setting up a trust is the best option, especially if your loved one can no longer make decisions.

New bill establishes federal office to oversee Alzheimer's

President Barack Obama signed the National Alzheimer's Project Act (NAPA) into law in January. Democratic Sen. Evan Bayh of Indiana and Republican Sen. Susan Collins of Maine introduced the bill.

According to the language of the bill, NAPA's goal is to establish a dedicated office that would accelerate the development of treatments for Alzheimer's disease. It would also help coordinate the health care and treatment of patients with Alzheimer's, as well as coordinate and provide information on Alzheimer's research across all federal agencies.

The director of the office would be appointed by the president. The director's duties would include creating and updating a national plan, as well as evaluating all federal programs dealing with Alzheimer's.

Additionally, the director submits an annual report to Congress assessing the progress of all nationally and federally funded efforts for Alzheimer's research, clinical care, institutional, and home- and community-based programs and outcomes.

The act also establishes an advisory council comprised of eight federal members including the surgeon general, as well as 12 non-federal members, including two Alzheimer's caregivers. NAPA was supported by the national Alzheimer's Association and local chapters across the country. The estimated global cost of dementia is expected to reach \$604 billion, according to a report released by Alzheimer's Disease International.

If that total were a nation's economy, it would be ranked 17th globally. North America and Western Europe will account for roughly 70 percent of those costs. The projected total is a substantial increase from previous estimates of \$315 billion in 2007 and \$422 billion in 2009.

The rise in cost results from an increase in the Alzheimer's patient population. Currently 5.1 million Americans are living with the disease. By mid-century, that number is expected to almost triple to 13.5 million.

This January, members of the baby boomer generation began turning 65. As baby boomers age, more are at risk of developing Alzheimer's or other forms of dementia. Age is the greatest risk factor, according to the Alzheimer's Disease International report. Without taking proactive measures, the disease could cost the United States healthcare system nearly \$20 trillion by 2050, according to the National Alzheimer's Association.

Dr. Duane Gross, CEO of the Midlands Chapter, said NAPA is a major step forward and a victory for anyone with symptoms of dementia.

Young adults use humor to cope with Alzheimer's disease

by Nick Cavallaro, Benjamin McCall and Brandie Simmons

Heather Stauffer uses humor to cope with her mother's Alzheimer's disease.

The 27-year-old graduate student at the University of Nebraska-Lincoln started her blog, "Old Jokes Get Still Get Laughs," shortly after her mother Carol's diagnosis in 2008 when Carol was 54. The following excerpt from December 2010 is typical of Heather's humor:

"My mother has always enjoyed M&M's, but over the last two years, this candy has almost become an obsession... Like a squirrel, she hides them around her room for safekeeping, and then forgets where they went. Some of the most surprising moments are when she emerges with a bag that seems to have appeared from nowhere."

Heather is among the many children affected by their parents' diagnosis of young-onset Alzheimer's disease. Her blog, she said, has helped her find support within an online community.

"I have found a welcoming audience online through my blog about our ordeal," Heather said. "The importance of a shared family experience cannot be understated."

Heather said she and her family knew very little about the disease before hearing the diagnosis. The subtle signs were there, she said, but she didn't recognize them at first. The diagnosis affected every aspect of her life, her father's life and her two sisters' lives.

"[My mother] no longer has any idea what the word 'Alzheimer's' means," Heather wrote in her blog, "but my father and I do, and that one word will change our lives forever."

Her youngest sister, McKenzie, wrote an entry on Heather's blog admitting that she didn't want to believe signs that her mother was sick. McKenzie even hoped her mother had a curable disease.

"In the back of my mind, I always thought it was Alzheimer's, but I wanted my mom to have a brain tumor," McKenzie wrote, "so when she had surgery to take the tumor out, she would be back to her normal self."

McKenzie, a 21-year-old student at the University of Nebraska at Kearney, said being a college student away from home makes her mother's disease harder at times.

"At times I feel out of the loop because the rest of my family is around her more often," she said, "so I don't know what changes they have made to help her out."

Heather said she and her sisters have come together during the hard times to help their father, Robin - Carol's primary caregiver. Her mother's disease, Heather said, has made her rethink her priorities.

"Staying close to family - in both physical location and as a family unit - is most important right now," she said. "The time I can spend with my mother is precious, and it is quickly running out."

Heather said her own young age makes the situation still more complicated. Young adults in their 20s typically deal with less serious issues, and these young adults don't expect to face their parents' mortality so soon.

Still, Heather said, maintaining normalcy is her primary goal.

"There are not many couples that have to deal with empty-nesting and Alzheimer's disease at the same time," Heather said, "but my father is determined to keep her in

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-Heather Stauffer

familiar surroundings for as long as possible."

The Stauffer sisters aren't the only children of young-onset Alzheimer's patients who have found solace in family. Tracy Schwartzkopf and Nickie Pistillo, daughters of Carol and Dan Karnowski, said dealing with the stress of their father's young-onset Alzheimer's is easier with humor.

"We don't laugh at [my dad]," Nickie said, "but at the things he does."

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Humor helps adult children cope with disease

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Despite attempting to stay light-hearted, both sisters said coping hasn't gotten easier over time. As Dan's condition worsens, their outlooks become less optimistic. Tracy said that though the coping process is more physically and mentally challenging than ever, it's also "easier in that we can laugh about things."

Heather Stauffer echoed this sentiment, writing in her blog that the disease is both complex and horribly simple:

"[Alzheimer's] is an illness of walking contradictions, false hopes, mistaken identities, guilt-ridden laughs, simple pride and sleepless nights. Though the final outcome is universal, the journey toward it is uniquely terrifying for each person."

Both the Stauffer sisters and Karnowski daughters stressed that the situation does not become easier with time. While circumstances may change, the disease progresses steadily, perhaps faster than the children are able to cope.

"The pain has changed from almost unbearable – after the diagnosis – to a chronic dull ache as I witness yet another task she cannot complete," Heather Stauffer said. "She is still my mother, and as long as she remembers her family, things don't seem to be as bad as they could be."

Coping through blogging



Heather Stauffer uses her blog, "Old Jokes Still

Get Laughs," not only to express herself about her mother's Alzheimer's disease, but to speak to others in similar situations.

"My goal for this blog is to share my family's experiences to not only present a personal look at this debilitating disease," she wrote, "but also show how life continues after the diagnosis."

It's important to find support for those diagnosed with Alzheimer's, but it's equally important for those affected – especially family members – to find their own support.

On her blog, which currently has eight subscribed followers, Heather provides humorous in-

sights into the life of someone living with an

Alzheimer's patient. She also shares links to other blogs and videos made by others in similar situations.

To read Heather's blog, visit: oldjokesgetlaughs.blogspot.com

tips for starting your own blog

- ✓ Set-up an account on a free blogging site such as blogger.com or tumblr.com.
- ✓ Choose a blog name that's as short as possible and easy to remember.
- ✓ Decide a theme for your blog posts, but feel free to deviate every now and then, remember your blog is supposed to be fun.
- ✓ Link to your blog on Facebook, Twitter and other social media pages.

Triggering early memories can strengthen mental, physical health

by JoAnna LeFlore, Mo Nuwwarah and Cory Schall

Everyone loves to be a couch potato, and many people try to get away with it as often as possible.

For people with dementia, leading an excessively sedentary lifestyle can lead to a vicious cycle of mental degradation. As people become more withdrawn, they tend to engage in less activity, which causes their mental health to decline.

"It leads to a downward spiral," said Patrick Bartmess, whose mother, Janet French, has young-onset Alzheimer's disease. "You don't think about things and there's no stimulation in the brain."

Participating in physical and mental activity is an important part of treatment for Alzheimer's. Keeping your mind active is vital, said Diane Hendricks, a social worker at the University of Nebraska Medical Center.

"Little things just to keep people engaged are effective," she said. "An example could be circling all of the A's in a magazine."

In the early stages of Alzheimer's, setting routines as a part of the person's schedule can help, she said.

The routine Patrick established for Janet was walking their dog twice a day around their neighborhood. He plotted a path that would be familiar to her.

Well-balanced physical activity is important, Hendricks said, and plenty of resources exist to help people stay active.

Dr. Daniel Murman, an associate professor in the department of neurological sciences at the University of Nebraska Medical Center, also agreed that following a routine can benefit someone during the early stage of dementia, along with physical exercise, a healthy diet, cognitive exercises and social exposure.

"Anything engaging the mind and

using the mind is useful," Murman said.

Patrick recently began taking his mother to their local YMCA, where she's a regular in a "silver sneakers" exercise program. The exercises focus on range of motion and cardiovascular health, using resistance bands, free weights and medicine balls. Patrick also plans to enroll Janet in an art class at the Sorensen Library.

"I really think exercise makes a huge difference," Patrick said.

For example, Janet performed the best she's ever done in a mental check-up from a doctor when she went immediately after a workout at the YMCA.

Games and puzzles involving sequence and concentration are also good for the brain, Hendricks said. She suggested beginning-level Sudoku puzzles or organizing a deck of cards. Janet regularly does crossword puzzles.

Doing things a person with dementia once enjoyed is also helpful, Hendricks said. Janet used to enjoy trips to the Loess Sandhills in Western Nebraska. Patrick and Janet now take trips to Mahoney State Park when the weather is nice.

"She grew up in rural Oklahoma, so I think that reminds her of her youth," Bartmess said. "She really opens up and brightens up in nature."

Murman suggested that journaling activities from recent hours in the day can also trigger early memories and strengthen memory skills. Patrick said his mother has become more reclusive recently, and raising her confidence level through participation in activities has been key to her mental and physical health.

"I think being engaged in different activities, especially with socialization included, keeps alive what's strongest in her brain," Patrick said.

Finding activities caregivers and people with Alzheimer's can enjoy together can be a challenge. Often simple activities work best. Some ideas include:

- **Taking daily walks** - As you walk, point out things you notice, like blooming flowers or other walkers. Help make the person with Alzheimer's aware of his or her surroundings.

- **Planning meals and cooking** - If it's safe and you've always enjoyed cooking, let the person with Alzheimer's handle simple tasks. As the disease progresses, cooking often becomes too complicated and even dangerous. Eating can be a challenge, too. Consider using white or light colored plates so the person with Alzheimer's can distinguish what's on his or her plate.

- **Enjoying a pet** - If you already have a pet, ask the person with Alzheimer's to help care for the animal. Even brushing a cat or a dog can be relaxing.

- **Reading out loud** - As a caregiver, consider reading short stories from a newspaper or magazine. If your loved one can still read, ask what he or she is enjoying most about the book.

- **Solving puzzles** - Working together, try to complete a crossword puzzle or even a jigsaw puzzle. Consider using puzzles designed for children.

- **Working outdoors** - Watering plants, working in a garden, mowing the lawn and pruning trees gives caregivers and patients with Alzheimer's a sense of accomplishment.