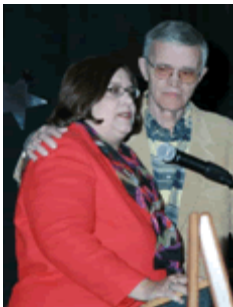


"News and Views" is a quarterly, online publication for caregivers, families and individuals with young-onset Alzheimer's disease and other dementias. Students from the University of Nebraska at Omaha's School of Communication, Fine Arts and Media wrote and edited the publication in conjunction with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

### 'News and Views' Creates Community, Fosters Strength

By Kathy Tewhill

Her name was Twyla. She was just 29 when a stroke left her speech slurred and her right arm and leg partially paralyzed. Despite some memory loss, she knew she had a 2-year-old daughter who needed her. As a young reporter, I wrote about Twyla more than 30 years ago, but I never forgot her. Once the story was printed, Twyla's husband called to say that Twyla felt she'd finally been heard. She believed she could be an example to others as she struggled through rehabilitation. Telling Twyla's story gave her a renewed sense of purpose and hope, he confided.



Today, I'm writing about my husband Tom Hurst, who struggles with young-onset Alzheimer's. His symptoms developed in his mid-50s. The disease has robbed Tom of his speech and comprehension skills. We struggle to communicate, and everyday tasks grow increasingly difficult. Once an avid reader, Tom can't enjoy the books we once shared because he can't remember the plots or decipher the words. As caregivers or people with this disease, we all have our own unique struggles. I believe that if we tell our stories, we will, like Twyla, find purpose and strength. Ultimately, we may even discover a sense of hope. In fact, that's what our newsletter "News and Views" is all about.

Journalism students at the University of Nebraska at Omaha are helping write and edit this newsletter, which is the first electronic newsletter in the country devoted to young-onset Alzheimer's. UNO journalism major Jason Sibson is the editor of "News and Views". When Jason was selected for the position, he said he wanted a cause to get behind - something that he could believe in and that would do some good. Jason plans to pursue graduate work in psychology after his December graduation. Call or e-mail Jason with your story ideas. As we work together, we can create a publication that's helpful and inspiring, but someday, I hope we'll be out of work. The day a cure for Alzheimer's is discovered will mark our last publication.

### Memory Walk 2009

#### Draws More Teams and Walkers

By Morgan Beachler and Holly Fredrickson

The Alzheimer's Association Midlands Chapter hosted its annual Memory Walk at the Chalco Hills Recreation Center in Omaha on Sept. 27. The Omaha walk raised about \$176,000. Fundraising associated with the Memory Walk officially ended on Oct. 31.

The walk was just one of many held across the Midwest each year and is a primary revenue driver for the Alzheimer's Association. Seventeen other cities held memory walks in Nebraska this year, including Columbus, Fremont, Grand Island, Kearney and Lincoln.

Larry Guenther, chairman of the board of directors for the Midlands Chapter, said that the Memory Walk represented a unique opportunity for those with Alzheimer's disease, as well as their caregivers. "It's an opportunity to realize that you're not alone in this, and it's a



chance for families to get together and spend time with each other," Guenther said. National statistics reflected a 23 percent increase in the number of teams and a 20 percent increase in the number of individuals working in local walks.

Last year's Memory Walk in Omaha attracted close to 2,000 people, and according to the Alzheimer's Association's official Web site, more than 200 teams registered in Nebraska for this year's round of events. Nationwide, the Alzheimer's Association hoped to recruit 30,000 teams. In Nebraska alone, 33,000 individuals are living with Alzheimer's and every 70 seconds, someone else in the country is diagnosed. Memory Walk is the nation's largest event to raise awareness and funds for Alzheimer's care, support and research.

"The walk raises awareness ... As the baby boomer generation ages, the numbers are rising of those affected," said Micah Evans, development director for the Midlands Chapter. "Fifty-four thousand caregivers are also affected and feel the pressure of this disease." Guenther estimated that most of those who attended and participated in the Memory Walk are caregivers themselves. "We get a lot of caregivers at these events. Sometimes there's three or four caregivers per patient," he said.

Like many who work for the Midlands Chapter, Evans has personal experience with the disease and can attest to the toll it takes on loved ones. His grandmother was diagnosed with Alzheimer's, and his father became her primary caregiver. "It was a 24 hour-a-day job," Evans said. Clayton Freeman, program director for the Midlands Chapter, is familiar with the far-reaching effects of Alzheimer's disease. "It affects the person who has it, but it also ripples out to a large group of people," Freeman said.

Ultimately, it is this far-flung ripple effect that might lead to a cure for the disease. As more people are diagnosed or know someone close to them who has been diagnosed, the Alzheimer's Association gains another ally in the fight to cure Alzheimer's. "It's a personal cause," Evans said. "It's more than just a job." Since 1989, Memory Walk has raised more than \$260 million for the fight against Alzheimer's.

## **Karnowski Family Adjusts to Disease, Enjoys Life**

By Jason Sibson

Carol Karnowski was sure Dan was just fooling around. It was the only way to rationalize how her husband, during a family gathering several years ago, couldn't grasp the rules and objectives of a simple game like Dominoes. "He could not catch on to it - the numbers, putting them together, things like that," Carol said. "Our in-laws were all there, my daughter from Des Moines and her husband and family were there too, and I just felt so embarrassed."



By then, Carol had been noticing other changes in her husband's behavior. He was neglecting to balance the checkbook when it was his turn, she said, and would sometimes ask for help spelling simple words. And she wasn't the only one to notice Dan's unusual behavior. "I was talking to my (youngest) daughter (Nickie)," Carol said, "and she said 'I think dad needs to go in for a physical. There's something going on here.'"

Carol heeded Nickie's advice and made an appointment with the family physician. Tests and X-rays revealed a mass on Dan's thyroid, and the doctor explained to Carol and Dan how fuzzy thinking is often associated with thyroid problems. The doctor hoped removing the mass would alleviate Dan's symptoms. But the problems persisted after surgery, and the couple visited a neurologist for further testing. The search for a diagnosis finally ended in February 2006, when 58-year-old Dan Karnowski was told he had Alzheimer's disease. "When we went to the neurologist and he said he has Alzheimer's, I lost it," Carol said. "I've never heard of anybody young like this having it. It really did scare me and I didn't want to accept it."

Carol is not alone. Up to 10 percent of people with Alzheimer's disease are young-onset sufferers, diagnosed prior to their 65th birthday. Approximately 400,000 people in the United States younger than 65 have been diagnosed with the disease. Alzheimer's causes severe problems with memory and behavior and can affect one's work, hobbies, social life and the ability to complete daily tasks.

Dan can attest to all of the above. Since his diagnosis three and a half years ago, Dan has been let go of his job. He lost his driver's license. He is able to stay by himself while Carol works, but relies heavily on his wife of 40 years when she's home. "He doesn't want to do anything by himself," Carol said. "Like, 'OK, do you want this window shut or do you want it open?' There is no decision he wants to make on his own."

Still, Dan finds enjoyment in his life. He and Carol regularly attend their grandsons' baseball, football and basketball games. Their two daughters and their families visit regularly and, with a greater awareness of Dan's disease since that night at the Dominoes table, have learned to accommodate and adjust for Dan's sake. Carol received a puppy as a birthday gift in March, and she said Dan and the newest Karnowski spend a lot of time together.

Carol finds comfort in the Alzheimer's Association of the Midlands' young-onset support group, which she's been a part of since last year. Carol went alone to one meeting, and has been accompanied by Dan for every monthly session since.

"The support group is a big help," she said. "When we break off into groups, with the caregivers in one section and the patients in another, I get a lot of ideas from the other caregivers, things that they have done and things that they have noticed." "It's good for both of us to see that, oh yeah; there are a lot of people dealing with this at an early age."



## Nebraska Leading the Charge in Alzheimer's Research

By Jason Sibson

Before 1970, Alzheimer's disease was virtually a mystery.

Alois Alzheimer made monumental strides in the early part of the 20th century when he described an "unusual disease of the cerebral cortex," which was affecting a patient in her 50s. But scientists neglected to follow up on Alzheimer's research, discarding the disease as extremely rare and a non-issue. We've come a long way.

Researchers at the University of Nebraska Medical Center now have entire divisions devoted strictly to Alzheimer's research. While a cure may not yet be on the horizon, doctors and nurses at UNMC are constantly developing and testing medicines and treatments in an effort to improve the way of life for those living with this progressive and fatal brain disease. Some 5.3 million Americans have been diagnosed today, a number that is expected to quadruple over the next 40 years.

"There's a lot of activity going on in Alzheimer's research right now," said Barbara Bayer, a research coordinator who has worked at UNMC for more than 20 years. "What they're doing is looking for new treatments, or looking for more effective treatments for Alzheimer's disease, and investigating new medications to see if they'll be helpful."

At UNMC, Alzheimer's patients must make it through pages and pages of exclusion criteria before being subjected to the medication or treatment under study. Dr. William Burke of the geriatric psychiatry division is currently heading a clinical trial that's testing a new oral medication, taken by the subjects every morning. Dr. Daniel Murman, a geriatric neurologist who works on UNMC's main campus, is working on an infusion trial that requires the subjects to come into the clinic for an IV every three months.

UNMC also boasts the Center of Neurodegenerative Disorders, which conducts some of the benchmark laboratory research on molecular characterization of brain disorders and the effectiveness of new therapies to treat them. The center recently discovered an enzyme with promising implications in the treatment of Alzheimer's.

And soon, the medical center will embark on a trial that will examine the potential of the Exelon patch, the first and only patch approved for the treatment of mild to moderate Alzheimer's disease.

"What they're looking at now is if a higher dose of that Exelon patch would be more efficacious as compared to a lower dose," Bayer said. "The new trial is specifically going to target people with moderate to severe Alzheimer's disease, not

the mild to moderate which many of the previous trials had."

Many of the trial medicines and treatments are targeting beta-amyloid, a protein found at the core of the neuritic plaques that are indicative of Alzheimer's disease. The amount of beta-amyloid, research suggests, is moderately related to the severity of the disease.

The trials have had some success, Bayer said, but there's still a long way to go. "It appears that these medications are lowering the beta-amyloid," she said. "The question is, 'does that make a difference in the long run?' There is a lot of research going on, but we still don't have that many answers."

## Technology and Structure Help Control Wandering

By Barry Glynn and Jason Sibson

It's everyone's worst fear - someone with Alzheimer's wanders away. In fact, it happened in Omaha. In 2007, Omaha World-Herald reporter Lynn Safranek told the story of Alzheimer's patient Alice "Nadine" Clark.

On the morning of Feb. 2, Safranek wrote, Clark was declared missing from her assisted-living apartment in Omaha. Two hours into the search, staff members of the assisted-living facility found her in an outdoor courtyard. She had inexplicably entered the Nebraska winter during its coldest hours and was stricken by hypothermia. She was taken to the hospital, but it was too late. At 79 years old, wandering cost Alice "Nadine" Clark her life.

For Alzheimer's patients and their caregivers, wandering is an ever-present threat. An estimated 60 percent of individuals afflicted with Alzheimer's disease will be involved in a critical wandering incident at least once during the progression of their disease, George Mason University assistant professor Andrew Carle said in a recent report on physorg.com. That means 21 million of the estimated 35 million Alzheimer's patients worldwide are destined to wander.

"It's probably the most frightening experience with Alzheimer's and it really puts the person and a caregiver at risk for some serious or fatal injury," said Diane Hendricks, a social worker with the Alzheimer's Association Midlands Chapter.

In public, wandering is usually a product of the person's surroundings. Unfamiliar places, large crowds and new environments, Hendricks said, are among the most common triggers. Within the home, wandering is often driven by a reversion to a person's former routine - in other words, to their life before the disease took over.

"Some of them get up in the morning and think they're still going to work," Hendricks said. "They really feel and are driven by 'I need to get up and go to work' because it's part of their long-term memory." To prevent or reduce the prevalence of wandering, Hendricks said, implementing a new routine and sticking with it is the key. "What we recommend often times to prevent it is to have a structure for the day - establishing a daily routine with some meaningful activities," she said. "If they don't have a routine they tend to go look for a routine."

The development of a plan within the home should also include ways to reduce the burden on caregivers who worry about their loved ones. In cases where the threat of wandering persists, a caregiver can take steps to limit the danger without having to follow the Alzheimer's patient around every moment. Putting locks on gates and fences around yards and patios are simple things a caregiver can do to regulate the boundaries of their home.

Technological advancements can help, too. Electronics outlets make affordable alarms that can be attached to any door and notify the caregiver when someone has passed through a doorway. In a steeper price bracket, you can find a portable GPS system with an unlimited on-demand locator that allows a caregiver to set up safety zones and acquire the device's location online or by text message. If the device is on the Alzheimer's patient, a caregiver can monitor their loved one without even being in the home.

Soon testing will begin on GPS footwear specifically designed to track down wandering adults suffering from Alzheimer's disease, according to a recent news.com.au report. If an individual is wearing the shoes equipped with the locator, the new technology will provide the location of that person - within a 30-foot radius - anywhere on the planet. Of course, the adjustment process for the family of an Alzheimer's patient is not complete without an increased understanding of their



loved one's motivation to wander. Coping with a parent, sibling or spouse who tries to leave the home, Hendricks said, means realizing that the Alzheimer's patient is not choosing to get lost.

"They don't know that they have a memory problem and that they will get lost, because they just don't have that insight," she said. "When we talk about that with folks and family members that say 'you know, they make these poor decisions and take risks and it's becoming a safety issue,' we tell them it's not because their personality is stubborn. "It just means that they don't have the insight to their deficit." Hendricks added.



## **Meeting With Attorney Essential Part of Post-Diagnosis Process**

By Jordan Haselhorst and Alee Cotton

Imagine living in a world where financial capability has escaped you. Money doesn't make sense anymore. Important numbers are beginning to slip away. For many of those living with Alzheimer's disease, this world is their reality. To ease the adjustment to this new reality following a diagnosis of Alzheimer's, it is important to seek legal advice as soon as possible. Alzheimer's affects the "two major issues with estate planning, disability and death," attorney William Brown said. The initial steps will be to immediately put in place a will, a power of attorney for medical and financial purposes and a trust. "These documents are very important with Alzheimer's disease because you can predict, with a fair amount of certainty, where the disease is going to go in a relatively short amount of time," Brown said.

A power of attorney comes in two forms: medical and financial. A medical power of attorney gives a loved one permission to make all medical decisions for another person, sign medical documents and make the call to terminate medical assistance. Financial power of attorney gives someone the ability to sign documents, write checks and make other financial decisions for a loved one. "If you appoint someone as your power of attorney, you darn well better trust them," said Jane Prochaska, Alzheimer's Association board member and former judge.

Giving someone power of attorney will eliminate the need to appoint a conservator, and having one in place will keep a lot of your personal information private. Of course, setting up these legal documents is not a simple process. Those preparing for a meeting with a probate lawyer should gather information beforehand. "For the initial meeting, you should bring with you any existing estate planning documents. If none exist, come with an idea of where your estate planning is going," Brown said. "You need to know the titling of your assets - this is very important."

Medical care can also become a legal concern with estate planning. Questions about who pays for the medical care will undoubtedly come up. "Some people pay down their estate or assets to their beneficiaries to get on Medicaid," Brown said. "Once that is done, the person generally must wait five years and apply for Medicaid." Along with these things, Prochaska said, a person with Alzheimer's should be gathering an idea of how much money he or she has, information about investments and a list of everything he or she owns. They should also collect a list of people named in their will, addresses and phone numbers of relatives and any strong preferences they may have about their burial.

Family members should be prepared to discuss how to cover the costs of care, what happens to a person when he or she

is disabled and what will be done with any assets left over. They should address concerns about whether the person with Alzheimer's wants to use a feeding tube or a ventilator, and if he or she wants a do-not-resuscitate order. The wishes of the person with Alzheimer's, Prochaska said, will be more easily granted through discussions with an attorney and the careful production of a will, a trust and a power of attorney. "If a person has Alzheimer's disease, at some point down the line questions come up," Prochaska said. "As hard as it is to talk about it, it's better when everyone knows when the time comes."

## **In Fight with Alzheimer's, Knowing Warning Signs Is Key**

By David Dockery, Abigail Pivovar and Mitchell Warren

Early detection of Alzheimer's disease allows caregivers to get a jump-start on care and treatment for their loved ones. Getting a jump-start - especially when dealing with young-onset Alzheimer's - can greatly improve the quality of life following diagnosis for a person with the disease. To detect Alzheimer's early, you must recognize and understand the warning signs associated with the disease.

The Alzheimer's Association Web site lists 10 of these "warning signs" - common changes in behavior observed during the onset of the disease.



**1: Memory.** The most commonly identified sign of Alzheimer's disease is changes in memory that disrupt daily life. Clayton Freeman, program director of the Alzheimer's Association Midlands Chapter, said memory changes are the classic sign. Individuals who exhibit this sign have trouble remembering recently learned information and may ask for the same information repeatedly. Those who constantly rely on memory aides, such as notes, may need to consult a physician for further testing.

"There are over 100 reasons why our memory slows down and many are reversible," said Diane Hendricks, a social worker at the Alzheimer's Association Midlands Chapter. Eliminating other health or mood-related problems may help determine whether Alzheimer's is present.

**2: Problem-solving.** Alzheimer's disease can make it difficult for people to make plans and solve problems. People who display this behavior find it increasingly hard to work with numbers and follow step-by-step directions. Tasks that were once simple, like following a recipe or paying monthly bills, may suddenly become more difficult with the onset of Alzheimer's.

**3: Confusion.** As a person ages, he or she may occasionally express confusion over new tasks. This does not automatically mean someone has dementia. If, however, a loved one starts to forget tasks that were once familiar, he or she may be experiencing warning sign number three. This symptom can easily be spotted when a person forgets how to complete tasks he or she has known how to do for a long time, such as driving to familiar locations. Hendricks said these changes can be among the most significant because the person becomes less independent because of them.

**4: Orientation.** The fourth warning sign, which includes having trouble remembering time or place, should not be confused with typical age-related changes like occasionally forgetting the day of the week. People who show this warning sign lose track of time, dates and even seasons. People in question who forget what day it is but figure it out later are probably not showing signs of Alzheimer's. People who forget where they are, though, may in fact be suffering from the disease.

**5: Spatial/visual.** Trouble understanding visual images and spatial relationships is the fifth warning sign. Do not confuse this sign with vision changes that may result from other problems such as cataracts. Those who exhibit this warning sign may have problems with perception, experience difficulty reading and struggle to determine contrast or color.

**6: Language.** New problems with words in speaking or writing are often spotted during day-to-day conversations with a person developing Alzheimer's. People may misuse words or call things by the wrong name. They may also have problems trying to join a conversation. Occasionally not finding the right word should not set off an alarm, but when this behavior becomes commonplace, Alzheimer's disease may be to blame.

**7: Retracing steps.** When someone misplaces things and loses the ability to retrace steps, Alzheimer's disease may be the issue. As with the other signs, this activity should only be seen as a problem when it occurs frequently or dramatically.

**8: Poor decisions.** Decreased or poor judgment, the eighth warning sign, can be recognized when an individual behaves in a way contrary to his or her previous behavior. This includes serious issues such as making poor financial decisions or forgetting personal hygiene and grooming.

**9: Social withdrawal.** One of the most visible changes a person with Alzheimer's disease can experience is withdrawing from work or social activities. This warning sign may occur when people stop participating in activities they have enjoyed for many years, such as hobbies or following favorite sports teams. People exhibiting this symptom may be avoiding outside contact because they are embarrassed or confused by the changes they are experiencing.

**10: Mood changes.** This warning sign can be hard to detect unless you spend a great deal of time with the individual. Those with Alzheimer's may experience seemingly irrational mood swings and reactions that are typically outside their comfort zone. Hendricks said family members of those with the disease often find dramatic personality changes one of the hardest symptoms to cope with.

It's important to remember that a person with Alzheimer's could be exhibiting just one or several of the warning signs. There is no particular order in which these signs occur, and no two cases are the same. "If you've met one person with Alzheimer's, you've met one person," Freeman said.

While the signs are a good starting point for diagnosis, those experiencing symptoms are encouraged to seek professional help to rule out any other diagnosis. "If you are worried about Alzheimer's, you need to get tested," Hendricks said. "If you continue to worry, that can do its own damage."

As Freeman suggests, the challenges faced by people with young-onset Alzheimer's are different because of their age. Young-onset patients often want to get involved and become advocates as "the new face of Alzheimer's."

Through early detection, younger people can help find a cure, outline future treatment plans and spread the word about Alzheimer's. "Knowledge is power when you are dealing with something like Alzheimer's disease," Freeman said. "The more you know the better."

## **Alzheimer's Association Task Force Marching On**

*The group aims to increase training hours required of professional caregivers.*

By Jamie Bell, Matthew Semisch and Erica Hess

A task force from the Alzheimer's Association Midlands Chapter met with legislators in Lincoln in August to address the need to improve training and education for professional caregivers of individuals with Alzheimer's disease.



(left to right) Clayton Freeman, Liz Johnson, Anna Fisher, Terry Johnson and Rosalee Yeaworth

The task force included people living with Alzheimer's, their caregivers and other Alzheimer's Association members. The group met with State Sen. Russ Karpisek and his assistant in Lincoln to push legislation through this year that will help those with Alzheimer's living in assisted living facilities.

Alzheimer's Association Midlands Chapter program director Clayton Freeman spoke at the meeting on behalf of his organization. "We need to make legislators aware of this disease," he said. "We need to make services more available (to those with Alzheimer's) and escalate our efforts."

The task force's top priority was to increase the number of hours of Alzheimer's-related training required of professional caregivers. Its platform centered on having at least four hours of training as a requirement for direct care staff and four hours for all other staff, including administrators. Two hours of continuing education would also be required as advancements are made in care-giving practices for Alzheimer's patients.

Those most affected by the legislation are the individuals with Alzheimer's and their caregivers. Terry Johnson, a member of the task force sent to Lincoln, chooses to care for his wife, Liz, at home rather than put her in an assisted living facility. Before the onset of the disease, Liz ran her own Kindermusik studio, an early childhood musical development program for children under 7 years old. She also taught private piano lessons. Because of the effects of Alzheimer's, she was forced to give up her musical pursuits.

Terry recognizes there will come a time when he cannot personally care for Liz, so he wants excellent care to be available to her when she needs it. "My two primary concerns would be competency and compassion," he said. "I would want her caregivers to be compassionate, and I would want them to know what they're doing."

This wasn't the first time Freeman and the Johnsons have met with politicians to encourage advancements in Alzheimer's care. Their ongoing march to increase awareness has included trips to Washington, D.C., to speak with other politicians representing Nebraska. Their efforts have contributed to the backing of a current bill in Congress to allow those under 65 to file for disability benefits if they are diagnosed with young-onset Alzheimer's disease. One supporter of this legislation, Freeman said, is Nebraska Rep. Lee Terry.

Through legislative actions such as these, Freeman said the Alzheimer's Association hopes to provide and enhance care and support for those affected by Alzheimer's disease. Currently, family and friends provide almost 75 percent of home care for Alzheimer's patients, and the economic value of unpaid care by family caregivers in 2007 was nearly \$500 million.

For Terry and Liz, working with the Alzheimer's Association allows them to provide assistance and encouragement for those in similar situations. "We'll keep on doing what we are doing, and that's taking it one day at a time," Terry said. "My future plans are to care for Liz and be with her day-in and day-out as we face this whole thing together, and that's really the long and short of it."

## **Vision Statement**

A world without Alzheimer's disease.

## **Mission Statement**

To eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.