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news & views staff

WRITERS & EDITORS

Mike Bell
Phillip Cohen
Natalie Davis
Emily Johnson
Katherine Leszczynski
Joe McCampbell
Kathryne Plaza
Richard Rider
Tiffany Riggs
Marie Schellenberger
Carleigh Smith
Kelsey Stewart
Alison Thomsen
David Waller

LAYOUT & DESIGN

Cameron Carlow

FACULTY ADVISER

Kathy Tewhill
tomkat530@hotmail.com

Shedding the Light



PHOTO BY MATT SCHUR

The Capitol Building in Lincoln was showered in purple lights on Sept. 21 in honor of World Alzheimer's Day. Lt. Gov. Rick Sheehy spoke to an estimated 40 people in attendance, which included caregivers, patients and health care professionals.

Families need to comprehend Medicare, Medicaid differences

By Tiffany Riggs and Kelsey Stewart

Navigating overwhelmingly complex government assistance programs is like learning to fly a plane without an instructor. Two of these programs, Medicare and Medicaid, are often used interchangeably but are actually different programs.

"The biggest challenge is understanding the difference between the two,"

said Cathy Wyatt, certified senior adviser and director of educational outreach at Financial Visions.

Medicare is a federal health insurance program. A person is entitled to Medicare at age 65.

The four different parts to Medicare include hospital insurance, health insurance, prescription drug coverage and Medicare Advantage Plans, according to

www.medicare.gov. Medicare Advantage Plans are additional plans offered by Medicare-approved private companies.

Medicaid is a program that pays for health care for those with limited resources and the disabled. A state determines eligibility and coverage. The federal government then reimburses

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Signs point to acceptance

□ By Kathryn Plaza and David Waller

Part of Myron Goede's job as a physicist was to service hospitals and doctors' offices, which meant Goede drove himself to those locations, Jayne Murray, his wife, said. At around 59, Goede started having trouble finding his way to the hospitals he'd visited time and time again. Goede was convinced there was nothing wrong with him and even became angry when his wife suggested he get tested.

One night, though, a state trooper found Goede pulled over at the side of the road, not knowing where he was. This incident helped Murray persuade Goede to get tested. As it turned out, Goede's disorientation was one of the 10 warning signs of Alzheimer's, according to a list compiled by the Alzheimer's Association: difficulty completing familiar tasks.

The Alzheimer's Association defined this sign as being unable to follow a recipe, play bridge or complete other everyday tasks, such as driving to a familiar location in Goede's case.

Other signs that Goede exhibited, Murray said, were losing things all the time and declining judgement.

Clayton Freeman, director of programs and services with the Midlands Chapter of the Alzheimer's Association, said people need to know the warning signs because the more people know, the better they can fight this disease. Family members of those with the disease need time to plan for their future.

Goede's experience demonstrates additional threats that come with ignoring symptoms. Murray said Goede could not drive safely and had gotten in several accidents.

"I wouldn't ride with him," Murray said.

Furthermore, Goede set dosages for radiation treatment for patients, and

doctors couldn't let him continue doing that, Murray said.

Freeman said the Alzheimer's Association helps patients and family members of those with Alzheimer's disease or any type of dementia. The association makes sure families are prepared financially and mentally by offering educational programs, support groups, a 24/7 hotline and training for professional caregivers.

There is a huge misconception that only old people get Alzheimer's, Freeman said. The youngest patient he encountered was around 30 years old. Age is a big factor, but it is not the only factor when it comes to Alzheimer's, he added.

Another misconception is that Alzheimer's and symptoms of dementia are a normal part of aging. They aren't, Freeman said. Many believe older people normally become senile and refuse to acknowledge something is wrong with their loved one. This is when memory loss comes into play. Freeman compared a person's memories to a file cabinet. Under normal conditions, it may take an older person longer to find a file because the file cabinet has gotten bigger, but the file can eventually be found. With Alzheimer's, the information is not accessible and a patient may be unable to locate the file.

"It's not just, 'oh I can't remember where I put my glasses,'" Murray said. Critical thinking, planning and organizing skills are gone.

This kind of memory loss affects the patient's daily life, Freeman said.

Alzheimer's is a fatal brain disease, not a mental illness, Freeman said. Alzheimer's patients can live between eight to 10 years with the disease, maybe even longer.

Personality changes are another

The 10 signs of Alzheimer's

1. Memory changes that disrupt daily life.
2. Challenges in planning or solving problems.
3. Difficulty completing familiar tasks.
4. Confusion with time or place.
5. Trouble understanding visual images and spatial relationships.
6. New problems with words in speaking or writing.
7. Misplacing things and losing the ability to retrace steps.
8. Decreased or poor judgement.
9. Withdrawal from work or social activities.
10. Changes in mood and personality.

major indicator of Alzheimer's, he said. For example, someone who never used to swear may now swear like a sailor.

Alzheimer's accounts for 70 percent of dementia cases, Freeman said. There are 70 types of dementia caused by different things: Parkinson's, vascu-

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Reducing the risk possible

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lar problems, Down syndrome and head trauma are some of the major causes. Doctors rule out everything else before diagnosing a patient with Alzheimer's. Freeman said doctors are aware that the most common misdiagnosis can occur with depression, thyroid problems, medication issues and not eating well.

Freeman said one of the major questions about Alzheimer's is how to prevent the disease from developing. Exercising, watching one's cholesterol, blood pressure and blood sugar, eating healthy and keeping socially and intellectually active can slow down the effects of Alzheimer's, but there is no way to prevent it entirely.

Individuals and families display different reactions when Alzheimer's is diagnosed. Typical feelings include denial, disbelief, shock and anger, but eventually acceptance sets in. In Goede's case, he was very angry about the diagnosis at first and thought the doctor was a quack, Murray said. Now, although he can be sullen at times, he accepts the disease and tries to be positive about it. Murray, on the other hand, felt relieved because she wondered whether her husband was willfully behaving this way. The diagnosis helped her better understand and deal with her husband's behavior.

Eventually, patients and families accept that Alzheimer's is a progressive, fatal brain disease that affects memory, learning, behavior and ability to perform daily tasks, Freeman said.

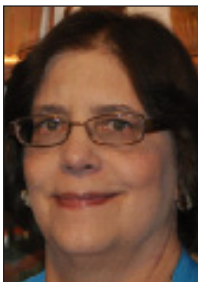
Patients should know what they have so that they can become educated about the disease and plan for the road ahead, he added. Some advocates are contacting state legislators to help get funding to fight this disease. "Knowledge is power," Freeman said. "The more you know about your opponent the more you can fight it."

Allan Schur, whose wife has Alzheimer's said, "I'd rather light a candle in the darkness than be in the dark."

After 3 years, battle wages on

By Kathy Tewhill

Three years ago this fall, "News & Views" made its debut. Our first issue was an experiment, really, to answer some questions. Could young college students write about a ruthless disease that typically affects "old people"? Were there enough topics to support a quarterly publication? Would caregivers and people with Alzheimer's willingly tell their stories?



Kathy Tewhill

Yes, yes and absolutely yes. In fact, we have much to celebrate with this publication, even as our personal battles grow more difficult.

Since the first issue of "News & Views," five classes have devoted time, energy and talent to create a professional publication. Students have swallowed tears interviewing people their parents' age who no longer remember how to tie their shoes, read or cook dinner.

As far as having enough stories ... well, each issue speaks for itself. Students continue to tackle difficult subjects that require multiple interviews and research. Students meet caregivers and feel inspired and yes, sometimes sad, as they see how difficult the task is.

Initially, some caregivers were reluctant to share very personal experiences. Caregiver Carol Karnowski and her husband, Dan, were the first couple students wrote a profile about. When I approached Carol with the idea, she didn't hesitate.

"Sure – at this point, why not?" she asked.

Now families want to be interviewed. Caregiver Allen Schur told the young-onset support group last spring that the UNO students were kind, caring and professional. "These are the journalists of tomorrow," he reminded everyone, "and maybe this experience will stick with them."

Mike Majeski, who has aphasia, and his wife, Kathy, wanted to "adopt" the students who interviewed them. I remember gregarious Tim Thompson, who has frontal lobe dementia, looking at a printed copy of an early newsletter and touching the students' names listed on the front page. "These are my friends," he said. "I pray for them."

Staff members at the Midlands Chapter go out of their way to provide information and schedule interviews with students. Each semester, Clayton Freeman or Rosalie Shepherd speaks to the class about the basics of the disease.

Like so many caregivers, I've been looking for hope since my husband displayed symptoms of Alzheimer's in his mid-50s. Tom is now 69, so I feel a little like Don Quixote battling windmills in search of that unreachable goal. But it turns out that I didn't have to reach very far. Hope was literally right in front of me – in the face of every student.

While "News & Views" hasn't uncovered a cure for the disease, each publication fills me with hope. Maybe somehow our newsletter has influenced a life, and, in some small way, made a difference.

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Positive outlook helps Stauffer family cope

By Natalie Davis and Emily Johnson



Carol Stauffer, front right, was diagnosed with Alzheimer's ten years ago.

Ten years ago, Robin Stauffer began to notice that his wife, Carol, was having difficulty performing daily activities. She struggled opening doors, changing clothes and putting things back where they belonged.

"She had a stressful job and there were times when she would ask me to help her with the computer," Robin said.

Robin also realized Carol stopped going out and spent more time sleeping than usual. Carol's symptoms grew worse over time, and co-workers began to notice. The Stauffer's daughters – Heather, 27; Sara, 25; and McKenzie, 21 – observed chang-

es as well.

Heather remembered watching her mother fumble to write a check and buy items after decades of handling the family's grocery shopping. Carol's supervisor at Nebraska Health and Human Services was also concerned as Carol lost confidence in her job, switched positions and then experienced memory problems.

"Her boss was saying she wasn't putting things back where they were supposed to be," Robin said. "I had to start helping her remember the code to get in the door [at work]. We knew it was a problem then."

The Stauffers decided to visit their family doctor.

"They did a spinal tap and then her doctors decided we might need a memory test done because he wasn't quite sure," Robin said. "We didn't pay much attention to Alzheimer's because we thought it was a disease for people in their 70s and 80s."

Their doctors recommended the University of Nebraska Medical Center for further testing. With the signs of dementia becoming more apparent, the Stauffer family was looking for answers, but not getting a direct diagnosis. They didn't know whether Carol was sleeping more because she was depressed or had a more serious physical problem, such as a brain tumor.

In March, 2000, Carol was diagnosed with young-onset Alzheimer's disease. The diagnosis was surprising for the Stauffers – Carol was only 54.

Unfortunately, signs of the disease appeared years before she was diagnosed. Robin recalled noticing the symptoms as early as 1998.

"It was a slow process," Robin said. "I couldn't ignore it. It's not like cancer, where you have a short outcome. This is a long-term disease, and I think we're starting to see signs in people with a lot younger ages, in their 50s and 40s."

After the diagnosis, the Stauffer family was relieved to have an answer, but not sure what to do with it. Carol was the first person on both sides of their family to have the disease.

Her mother's diagnosis didn't

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Profile: Stauffers support each other

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catch McKenzie caught completely off guard. She said she knew Carol's symptoms were consistent with Alzheimer's. The changes in their relationship have been significant.

"My mom's Alzheimer's has negatively changed my life by not having the mother daughter talks we use to have," McKenzie said. "Although I can still talk to my mom, she is not able to give me advice or really comprehend what I am talking about. Since my mom's diagnosis, I have grown to

appreciate and respect her more. My mom did a lot for me [when I was] growing up, and now the roles have reversed."

Her older sisters had more difficulty accepting the situation.

"(Sara) and I had quite a bit of denial for a while," Heather said. "We wanted a different diagnosis because when you get that Alzheimer's diagnosis, you can't have a cure."

Because Carol was diagnosed years after showing symptoms of Alzheimer's disease, the Stauffer family now wants to help educate people to recognize the symptoms more quickly and get diagnosed early.

Seeing where you're at in your retirement, how long you can work and how long you can access health insurance are all very important, Robin said. Families and caregivers must decide whether they can or want to care for their loved one at home or struggle with the rising costs of nursing homes and health-care facilities.

"For me, it's the economic side of it. I'm really scared of having to send someone to a nursing home

with the high medical cost," he said. "It's not going to get any better, so you have to figure out what you're going to do."

Robin met with an attorney at a monthly support group who helped

"(Sara) and I had quite a bit of denial for a while. We wanted a different diagnosis because when you get that Alzheimer's diagnosis, you can't have a cure."

Heather Stauffer

the Stauffers get their finances in order. Most people don't know how to organize their wills and trust funds, let alone keep up with the latest medical research. Medical trials for new drugs are options for people who are in the early stages of Alzheimer's.

"We need money for research, but we also need to make people aware," Robin said. "We need to show people this is what can happen, and we need to be prepared somehow."

When Carol was diagnosed, the Stauffers didn't have long-term health insurance. Robin was unemployed at the time, and until then, the couple had been very healthy. Costs quickly escalated. Heather stops by frequently to help her parents, but not everyone has family nearby, Robin said. Support groups and community outreach programs help too, but very little support is offered in Fremont, the Stauffer's home town.

"Nye Legacy is supposed to be part of it (and) we use their facilities, but I need something in the daytime when I have to work," Robin said. "And it's mostly geared toward the

elderly. I keep telling them there's another group of people out there. That's what I'm frustrated with in this town. We don't have daycare centers for Alzheimer's, at least good daycare centers like Omaha does. It's really not that affordable. It would really help Carol a lot if I could get her in one of those because they do exercise and this and that, and she needs that."

The family tries to attend support groups and stay involved with community awareness

and fundraising efforts as much as possible. In fact, the Stauffer daughters recently helped establish the Young Alzheimer's Advocacy (YALZA) group. The group helps people under 40 cope when a loved one is diagnosed with Alzheimer's.

"Along with Patrick Bartmess, we formed this group to spread awareness about the growing epidemic of Alzheimer's disease to engage young adults in advocating for research funding and legislation for caregivers, and to connect with others who have been affected by this disease," Sara said. "This group is still very new, but we have a lot ideas that we are excited to be starting soon."

Sara lives in Omaha and usually attends monthly support groups, and the Stauffer family recently participated in the Midlands Chapter's 2011 Walk to End Alzheimer's on Sept. 25.

The daughters have also reached across state boundaries to spread awareness. Heather, Sara and McKenzie created a blog about Alzheimer's

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Anger, guilt part of caregiving

By Marie Schellenberger and Carleigh Smith

Editor's Note: The caregiver interviewed for this story will be called Dave Jones to protect his privacy.

"I thought I could deal with it—that it would be easy," Dave Jones said. Jones cares for a loved one who was diagnosed with young-onset Alzheimer's disease about four years ago. Jones knew his new role would be difficult, but he thought he'd be able to deal with the little things, like repetitive questions, that characterize the disease. As time went on, Jones realized even the most predictable symptoms sometimes triggered feelings of frustration and anger, followed closely by guilt. And he's not alone.

Diane Hendricks, a social worker associated with the Midlands Chap-

ter of the Alzheimer's Association, explained that although most caregivers struggle with these negative emotions on a regular basis, many avoid talking about them. But if these emotions aren't discussed, caregivers can experience mounting stress and even depression.

More than 70 percent of caregivers show underlying signs of depression and haven't established coping strategies to deal with these emotions, Hendricks said. Built-up frustration commonly results in terse responses, a negative attitude or even argumentative comments. Naturally, many caregivers feel guilt or remorse after expressing frustration with their loved one because, as Hendricks said, irritat-

ing behaviors "are the disease, not the person."

Hendricks stressed that every individual handles the caregiver role differently and must determine how to cope. The first step caregivers should take is educating themselves about the disease and asking their loved ones the hard questions. What are their concerns for the future? What specific needs should be addressed? What are they most afraid of?

If possible, it's best to talk about these things in the early stages of the disease, Hendricks said. Communication is key, and as it becomes more difficult, caregivers find comfort knowing they're following their loved ones'

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PHOTO BY KATHY TEWHILL

Diane Hendricks, a social worker associated with the Midlands Chapter of the Alzheimer's Association, hugs a member during a support group meeting.

'Guilt is overrated' in the life of a caregiver

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wishes. Hendricks suggested that caregivers always “hope for the best and plan for the worst.”

As the disease progresses, caregivers face more and more stressors. A loved one's repetitive questions, mood swings and confusion become harder to handle over time and are “really draining,” Jones said. On occasion his frustration has led to snappy responses and angry behavior, then he experiences guilt and anxiety for hurting his loved one's feelings.

The real question is what to do with those feelings. “Don't be so hard on yourself. Everyone has these feelings in stressful situations, and I can't imagine a more stressful situation,” Hendricks said. Feeling guilty is understandable, but it's important not to dwell on guilt because the actions you regret weren't intentionally harmful, she explained.

To dispel his feelings of regret, Jones reminds himself that “every day is new — I cannot take it to the next.” Hendricks agreed, telling caregivers that in the scheme of things, “the good you do outweighs the bad.” She asked caregivers to consider, “How long do I want to spend thinking about how guilty I feel?”

Hendricks offered tips for dealing with stressors that go hand in hand with caring for someone with Alzheimer's. When dealing with repetitive questions, it's easier to distract the person from the topic by changing his or her focus. She recommended connecting to the past because those memories will linger longer. Another way to distract someone is to suggest doing something he or she might enjoy, such as taking a walk or drive, looking at photos, playing music or giving the person a simple task to complete, such as folding laundry.

Since the distraction method isn't always effective, the second-best option is to ignore the repetitive questions. It

might sound callous, but according to information provided by Home Instead Senior Care, the questions are likely to stop when not reinforced by a caregiver's reactions. This method might be beneficial for caregivers and anyone

“Don't be so hard on yourself. Everyone has these feelings in stressful situations, and I can't imagine a more stressful situation.”

Diane Hendricks

with the disease by preventing mutual irritation.

Other behaviors exhibited by people with Alzheimer's disease, such as picking at clothing, fidgeting, wandering aimlessly and asking repeated questions, all have a common denominator — stress. To manage these behaviors, it is important for caregivers to figure out where their loved one's anxiety is coming from, acknowledge it and empathize with their loved one to show support.

To relieve stress, caregivers should use the resources they already have — talk to friends and family and ask them to help if possible. Hendricks urged caregivers to use their support systems and talk about their feelings with someone they feel comfortable with and trust.

Taking a break is always a good idea, as well. Jones said he steps out of the room and takes a deep breath

before reacting to a stressful situation with his loved one. It's also helpful to get away, go a movie or walk his dog in the park. Scheduled weekly activities for his loved one give them both alone time, keeping their spirits up and giving structure to the new life they're leading.

It's not always easy to find alone time. Hired caregivers are expensive. Caregivers can try signing a loved one up for volunteer work, church activities or fitness clubs instead. These experiences are economical and rewarding. According to information from University of Nebraska Medical Center Physicians, activities like these also encourage reasonable autonomy for people with Alzheimer's disease, something they don't experience often.

Though caregivers are most concerned with the well-being of their loved ones, they must also remember to take care of themselves. Jones has a plethora of methods to deal with his stress that could work for other caregivers. He blogs about his experiences on both public and family sites, visits support groups regularly and keeps his body and mind healthy by doing yoga, speaking to a counselor and practicing brain strengthening exercises. He also expresses his emotions through painting and playing music, and taking heart from the “really simple pleasures,” Jones said. Developing his spirituality has helped him through these tough times, he added.

It's clear that caregivers will become frustrated from time to time and may feel guilty about angry reactions, but like Hendricks said, these natural human emotions can be learned from rather than just regretted. She suggested being mindful rather than guilty about these emotions and looking for their triggers to learn from the bad days.

Her final bit of advice? “Guilt is overrated,” Hendricks said.

THE ROAD TO THE CURE



PHOTO BY MIKE BELL

About 128 teams of walkers turned out at the Chalco Hills Recreation Area to support the Walk to End Alzheimer's, enjoying the perfect weather in their effort to raise money for research.



PHOTO BY THE MIDLANDS CHAPTER

More than 37,000 people in Nebraska and 69,000 people in Iowa are living with Alzheimer's disease.



PHOTO BY THE MIDLANDS CHAPTER

The members of the young-onset Alzheimer's support group cut the ribbon to being to walk.



PHOTO BY THE MIDLANDS CHAPTER

President and CEO of the Alzheimer's Association Midlands Chapter Duane Gross was interviewed.

Staying positive essential for Stauffers

(Continued from page 5)

er's-related news and stories to inform and connect people interested or personally affected by the disease.

"Blogging seemed like a good medium for sharing experiences in short, manageable bits to a large audience," Heather said. "Since this is a new experience for most people, I wanted them to get a glimpse into this gut-wrenching experience without being overwhelmed. The fan base is still pretty small, but there are a lot of loyal readers who have been very supportive."

Last April, Heather and Sara traveled to Washington, D.C., to represent the Midlands Chapter at public policy forums and at the Alzheimer's Association National Advocacy Conference.

"We talked to our representatives to see what is coming up as far as legislation and say why it's important for them to support this legislation," Heather said. "It's been really important in the last year or two, and we were really excited that there was a lot of interest finally. We got to see what people want to see happen. That's really good to see what is going on outside of our community."

Sara agreed, and said the experience has helped open her eyes to the world of research and advocacy for Alzheimer's disease.

"I know Heather and I came away with the sense that we had a mission to accomplish back home in Nebraska to increase awareness of Alzheimer's disease to our generation of young adults," Sara said.

Having a loved one with Alzheimer's disease is hard, but the Stauffer family believes staying positive is essential. Robin especially sees the value in staying optimistic, but admits it's one of his biggest challenges. He's assumed responsibility for many activities Carol used to do, such as grocery shopping, making doctors appointments and housekeeping.

Carol and Robin still keep connected to the community by going to church functions, although they don't go out as much and friends don't call as frequently, Robin said. Support groups help Robin and Carol remain upbeat, but the biggest support comes from their three daughters.

"Communication really helps the brain and it eventually won't work, but at least I think we're trying," Robin said. "I think the other biggest challenge is keeping a positive outlook. I sometimes get short-tempered, but you can't. I think if you can find people to talk to, that's a big thing. Don't get in a hurry about things - just go from day to day."



PHOTO BY MIKE BELL

Participants not only walked during the day's events, but enjoyed the rest of the park, with children's activities and music. Pets were allowed to walk, too.

Easy exercise important to patient, caregivers' lives

□ *By Cameron Carlow and Joe McCampbell*

"No pain, no gain" may be an expression used to describe exercise, but in the case of Alzheimer's patients or their caregivers, no pain is needed.

Recent medical research is focused on finding out how exercise protects the brain, but nothing is certain. "There is mounting evidence that shows that much of this is because of genes and some of it is lifestyle. The way people live their lives shows a connection between body health and brain health," said Rosalie Shepherd, Southwest Iowa's outreach coordinator for the Alzheimer's Association.

With no cure in sight, medical professionals recommend exercise to maintain physical health.

"You will read that activity is good. It is really inconclusive, though," Barb Bayer, nurse and Research Coordinator at University of Nebraska-Medical Cen-

ter, said. "Yes, it is definitely helpful. It is a good thing to do, but the research that has been conducted isn't so sure. We don't yet know what the relationship is."

Technology today is vastly different and can be used to benefit Alzheimer's patients. A study was conducted to find the relationship between the Nintendo Wii, a video game console, and weight loss. The Wii Fit was helpful in reducing people's weight along with diet. The same holds true with Alzheimer's. "The Wii Fit is great. People have enjoyed it and it increases activity," Bayer said.

Other inexpensive exercises will work if Wii Fit is out of the question. "Besides swimming, walking is probably the best exercise," Shepherd said. "If they just walk around the block it would help them a great deal."

Exercising with someone who has Alzheimer's

may prove difficult at first, but Bayer suggested using exercises that mirrored the way a person lived before Alzheimer's took its toll. "Draw on what the person used to do before. See if they are still able to do physical activity that they used to do. Keep them active on a day to day basis," Bayer said. "The most important thing is not to wait on them but allow them to do what they can for themselves."

At first, it may be difficult to see the benefits of exercise because anyone with symptoms of dementia needs repeated instructions and has experienced loss of muscle memory, but Bayer encouraged caregivers to be enablers, not disablers. Offer positive reinforcement and match capabilities with expectations. Never get frustrated with a loved one's diminishing capabilities.

That's why Shepherd recommended walking – it's

something patients and caregiver can enjoy together. The caregiver experiences high stress levels that come with the territory of caring for a person with Alzheimer's.

"Exercise is just as important for the caregiver as it is for the person with Alzheimer's," Bayer said. "Just because they don't have Alzheimer's doesn't mean they aren't dealing with the stresses of it."

Releasing energy, blowing off steam or simply staying healthy and fit all benefit caregivers, who play a vital role in the day-to-day life of someone with Alzheimer's. The caregiver role can be a 24/7 operation, so finding time to exercise is important to the well-being of the caregiver and the person with Alzheimer's, Shepherd said. "One doctor told me "I lose more caregivers than I do (Alzheimer's) patients."

Tips for making walking enjoyable include:

- Making sure caregivers and their loved ones have comfortable shoes
- Taking time to stretch first, even before short walks
- Understanding how long the loved one can walk and start with that modest goal
- Increasing walking time gradually
- Paying attention to nonverbal cues – shortness of breath is a sign to walk more slowly or take a break
- Pointing out seasonal sights along the way, like the leaves turning color in fall
- Dressing appropriately
- Using shopping malls for walking if the weather is uncomfortably cold or even hot

A touch, glance worth a thousand words

As speech fades, nonverbal communication is a silent healer

□ *By Katherine Leszczynski and Alison Thomsen*

Ninety percent of communication is nonverbal. What happens when we lose the other 10 percent of vocal communication and rely solely on the nonverbal? Because some Alzheimer's patients lose their ability to translate thoughts into words, nonverbal communication may be their only option.

Nonverbal communication includes hand gestures, vocal tones, facial expressions and body language. Caregivers, nurses and loved ones must pay attention to all these signs to better understand a person with Alzheimer's who has lost his or her language skills.

Jackie Anderson, R.N. director of nursing at South Haven Living Center, says there are ways to make nonverbal communication work. Below are a few tips to enhance communication between caregivers and those with Alzheimer's or other dementias.

Offer a positive approach

No one appreciates being approached by someone who is angry or agitated, and no one likes someone with a demeaning manner. Though Alzheimer patients, in some cases, may be unable to form and understand words, they can pick up on emotions. Sometimes the way a person approaches can make all the difference.

"People with Alzheimer's can have a fight or flight tendency," Anderson says. If Alzheimer's patients are approached in a way that makes them nervous or uneasy, they will begin to feel the same way. If they are approached with a warm smile and gentle tone, they will be co-

operative and feel more relaxed.

"A smile and a kind, caring look can make all the difference. It shows them everything is OK."

Anderson adds that when approaching an Alzheimer's patient, walk at a comfortable, measured pace that suggests friendliness and talk to them at eye level. "When I'm talking down to you, it doesn't make you feel like an equal, so we get down and talk with them on their level."

Objects can help

Sometimes, it is beyond someone's control when it comes to communicating with someone suffering from Alzheimer's. That is when objects, such as signs, different colored carpet and pictures come into play.

"Some of our patients were having a hard time finding their rooms," Anderson says. Her staff laid different colored carpet in certain areas or put different pictures on the doors to helping patients find their way.

Anderson has even seen situations where patients rely on toys to help set their routine. Female patients sometimes find comfort in baby dolls.

"They believe they are really caring for that child," Anderson says. The patient's day then forms a routine around the "child." To an outsider, this might look a little strange. "Some people think 'You're giving them toys to play with?' And yeah, we are, because if that is what comforts them and helps them to communicate, we're going to support it."

Give choices

Just because Alzheimer's patients may find it hard to voice their thoughts doesn't mean they have lost their opinions or feelings. While it can be hard for them to voice concerns, nonverbal behaviors can be just as meaningful.

One way Anderson and her staff at South Haven Living Center ensure that Alzheimer's patients are given choices is by making choices simpler. "We will sometimes hold two outfits up for them. Some don't voice which one they want, but a simple smile at one over the other can show us which one they prefer."

Go with the flow

All Alzheimer's patients are unique. What works for one may not work for another. And what works one day for someone may not the next day. This disease leaves people constantly changing. Caregivers need to adapt to change.

"It is no fine art," Anderson says. "No one has said 'I can talk to all the Alzheimer's patients.'" Anderson says that caregivers often find methods that work for Alzheimer's patients, but it may not last long. "It may change tomorrow but even if it works for a while, we all get on board." Because nurses and caregivers find what works for certain people, keeping a consistent staff that is spontaneous and willing to learn about their patients is important. "Live in the moment and have fun," Anderson advises.

Respite care benefits patients; caregivers discover 'me' time

By Phillip Cohen and Richard Rider

Omahan Terry Johnson has been the primary caregiver for his wife, Liz Johnson, since she was diagnosed with young-onset Alzheimer's disease almost four years ago. Johnson is also a part-time professor at Grace University in Omaha. Caregivers like Johnson learn very quickly that they can't do it all. That's when respite care is needed.

"I use respite not only so I can take breaks, but because I have to work. It doubles as essential primary care for Liz." Johnson stresses how essential re-

spite care is for every primary caregiver. He says eventually the primary caregiver will be doing all of the cooking, cleaning, laundry, dressing and bathing, so taking breaks is imperative.

"I'm tired. I should use more respite. One thing that has helped is that Liz sleeps through the night. If she didn't, I wouldn't be able to get my rest and caring for both of us would be impossible," he says. Currently, Johnson uses about 26 hours of respite each week and his daughter helps whenever she can.

Respite care is a great way to have some time for yourself, while knowing that your mom, dad, sister, brother, husband or wife is always going to be safe and in the great company of a respite caregiver.

Dr. Anna Fisher, who specializes in dementia care, agrees with Johnson that respite care is essential for people

caring for loved ones with dementia. Fisher urges caregivers to learn about all available resources concerning respite care.

"If you try to do it all yourself, you will end up getting sick, too, and

both of you will need primary caregivers," she says. Of course, cost can be an obstacle to many people who need respite. "There are so many grants available through foundations such as the Alzheimer's Association and organizations such as ENOA, The Eastern Ne-

braska Office on Aging, offer limited care assistance programs for people in

need." Fisher advises people to look at all options at the beginning of a diagnosis and find a plan that works best for them.

As the Alzheimer's disease progresses, a caregiver should be aware that he or she doesn't have to deal with the symptoms alone.

Matt Mainelli, the manager of marketing at Home Instead, a respite care company based in Omaha, says that a primary caregiver should never feel alone,

and it's in a caregiver's best interest to experience time away from their loved one so they have some "me" time. "Me" time is very important, not only for the sanity of the primary caregiver, but also his or her health.

Respite care gives caregivers an opportunity to get out of the house to run errands, catch up with friends, go to work or even just take a nap. "Respite care is a great way to help out you and your loved ones. We have very flexible scheduling with our clients, some people use us three hours a week, while others use us 24/7, 365 days a year," Mainelli says.

The reason Home Instead and other groups offer in-home care is because dementia and Alzheimer's patients can not handle the everyday tasks of being by themselves, taking a shower, making food or doing the laundry. Respite care provides a break in the day for caregivers to have time for themselves.

Karl Kosloski, a professor of gerontology at the University of Nebraska at Omaha, says primary caregivers can develop stress and health related issues if they are not giving themselves time off.

Kosloski says there are three types of burdens that caregivers could encounter while nursing a loved one with Alzheimer's. The first burden, called objective, occurs when

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Karl Koloski, PhD

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Respite care helps relationships, relieves caregivers' stress

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the caregiver tries to do too much for the loved one. The second burden, relationship, occurs when the primary caregiver is no longer getting along with the member of the family who has the disease. This happens when the person

with the disease grows argumentative, no longer recognizes the caregiver or feels threatened by attempts to help.

The final burden is stress. Stress occurs when the caregiver realizes his or her loved one is going to die. Sometimes

the stress of caretaking overwhelms the caregiver and they feel more pain helping their loved one.

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Medicare, Medicaid provides health insurance to many

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the state for part of its expenses.

According to the New York Times, Medicaid has the largest number of recipients of all health programs in the U.S., serving 56 million people.

Medicaid differs from Medicare because an individual must financially qualify. A Medicaid applicant's assets must reach a fixed amount, which varies from state to state. In Nebraska, a person's assets must be at or less than \$4,000. In Iowa, a person's assets must be at or less than \$2,000.

"One of the biggest problems is when people wait to talk to an adviser and spend down their assets that could have been saved," said Mark Guillatt, the founder of Nebraska Medicaid Planning and a certified financial planner.

Someone would apply for Medicaid when assets meet state requirements. Medicaid applicants must be in need of long-term physical care and financial assistance. Timing can have an impact on the application process, which can take several months to complete.

"Even when it comes to applying for Medicaid, planning is key," Wyatt said. "For example, the application process can take months. If an older adult waits until the last-minute, they must then wait for approval before receiving the care they probably needed yesterday."

The best thing families can do to prepare for a situation requiring Medicaid is to have appropriate long-term

care insurance, Guillatt said. This is something that needs to be done early in life because at a later age, people don't qualify.

"We are all going to age," Wyatt said. "Start preparing today."

Before applying for either of these programs, Wyatt and Guillatt recommend consulting a professional.

"Seek professional counsel from a team who understands income planning, asset protection, Medicare, Medicaid, Alzheimer's and related dementia and can assist in navigating the system," Wyatt said. "Most importantly though, a team who has your best interest at heart."

Finding a knowledgeable adviser can be a challenge. The system is complex and requires experience to navigate successfully.

"Ninety percent of advisers don't know how the Medicaid system works," Guillatt said.

Ways to find a credible adviser include asking potential adviser show many Medicaid applications they have filled out. Guillatt advises people to ask for references or testimonials. Also, ask what a financial planner's outcomes with Medicaid have been.

"If they have really helped people, then they have references and testimonials and thank-you letters," Guillatt said.

According to the New York Times, Medicaid provides health insurance to one in five Americans at some point each year. In 1964, when Medicaid

For additional help:

Medicare:

- Social Security office, www.medicare.gov

Medicaid:

- A professional who understand the law (doesn't necessarily need to be an attorney). "Medicaid education is key in short-term and long-term planning," Wyatt said.
- Department of Health and Human Services
- Access Nebraska, www.accessnebraska.org
- Nebraskamedicaidplanning.com

was established, the costs planners envisioned are still in place today, even though the costs are substantially different.

"Medicaid rules defy common sense," Guillatt said. "There is a whole different dynamic."