

Dealing with a new reality; Many want to see more attention brought to Alzheimer's

By Anthony Kuipers, Daily News staff writer | Posted: Saturday, November 8, 2014 12:00 am

The signs usually start out small.

All of a sudden, one can't remember a previous conversation, or that time they met a friend for breakfast.

The brain can no longer record certain events and information.

"It's like getting so drunk, you lose an entire night," said Judy Cornish, founder of Moscow's Dementia and Alzheimer's Wellbeing Network (DAWN).

Once they realize what's happening to their mind, those with Alzheimer's Disease go through a scary and frustrating phase.

They either realize what's going on, or don't, and believe the people they interact with are making up stories.

"They end up either terrified to realize they can't trust their own brains or they end up absolutely frustrated and very angry that everyone else around them is trying to make a fool out of them," Cornish said.

That's why it can take time for people to get a diagnosis, she said. Instead of confronting their disease and seeking help, some may choose to isolate themselves.

Mickey Hale, a specialist for Gentiva, a home and hospice service, said some don't want to admit they have a problem, and those close to them don't know how to deal with the situation. That's why, almost ironically, it often takes someone else to convince them they need to get a diagnosis.

"When a complete stranger says 'You have Alzheimer's,' all of a sudden, they listen," he said.

Many are afraid others will find out, as the disease still carries a stigma with it. Cornish likened this fear to the fears surrounding HIV 20 years ago. It can be especially difficult for those who live in an area like the Palouse, where news can travel quickly.

"It's really hard to get people in a small town to talk about dementia," she said.



Dealing with a new reality

Certified nursing assistant Bonnie Walker demonstrates an activity with a ball that she typically does with residents in the Special Care Center at Good Samaritan Village on Thursday in Moscow.

Two cousins

Moscow resident Karen Davis said two of her cousins have been diagnosed with dementia, and one of them has Alzheimer's. One started showing signs about three years ago, but was reluctant to let anyone else know.

"One was so relieved when her family finally figured out what was going on," Davis said. "She said 'I don't have to hide it anymore.' "

Maybe these families can rest easier knowing they are not alone.

It is the most common of all known cases of dementia. One in nine people 65 and older are diagnosed with the disease, according to the Alzheimer's Association. November is National Alzheimer's Disease Awareness Month and National Caregiver Month to shed light on the more than 15 million Alzheimer's and dementia caregivers in the US.

It projects 97,000 people in Washington in that age group have the disease, while 22,000 have it in Idaho.

In 2010, Washington had the highest age-adjusted death rate for Alzheimer's disease in the country with nearly 44 deaths per 100,000 people, according to the Centers for Disease Control. It was the third leading cause of death in Washington from 2009-10. Idaho had a death rate of 26.8.

"If you look at the number of people in the United States with it, it's an epidemic and we're not paying any attention to it, or little attention to it," Cornish said.

The Alzheimer's Association has encouraged state governments to develop a plan to meet the needs of its citizens with Alzheimer's. Idaho developed a written plan in March 2013 with goals to raise awareness, provide education and coordinate services for patients, families and caregivers.

Washington is in the process of developing a plan, said PJ Christo, outreach coordinator for the Alzheimer's Association.

Fortunately, there are local resources available for patients and caregivers, including DAWN.

Caregiver training

Cornish's staff trains families and caregivers to care for their loved ones. They also visit the patient's homes, and help them accomplish daily tasks, such as running errands and paying bills.

Davis worked with Cornish and appreciated Cornish's expertise on the disease.

She told Cornish it was frustrating hearing her cousins ask the same questions over and over as their memory faded. Davis said Cornish told her this behavior is normal, and her cousin needs the information, but simply cannot retain it.

"That has helped me to be more patient," Davis said.

Circles of Caring, an adult day health service, has support groups in Pullman and Moscow two times a month, as well as a monthly education series designed to help caregivers understand the various stages of disease progress and keep their loved ones safe, according to their website.

The local branch of Gentiva, based in Clarkston, offers its services to Whitman, Latah and Nez Perce counties.

Moscow's Good Samaritan Society offers 12 beds dedicated to those with dementia, said spokeswoman Jan Ahles. The doors which lead to the Special Care Center have sensors to alert staff when opened. This helps to keep residents from wandering without supervision.

The Alzheimer's Association provides support groups for caregivers around the Inland Northwest, though they currently don't provide any in the Pullman and Moscow area. PJ Christo, said she is working to change that and hopes to hire a couple staff members to start a support group in Moscow in 2015.

They currently offer online support and a 24-hour phone line caregivers can call.

Massage therapy

Christine Dopke, an 18-year licensed massage therapist, offers to go into homes and provide massages to dementia patients and their caregivers in Moscow and the surrounding Idaho communities. Though they may not be able to communicate effectively, she can tell her sessions relax the client and give them a positive boost.

"When you touch them, you can feel their happiness," she said.

But, according to specialists, there's always more that can be done.

Hale and Ahles both said the area could benefit greatly from an entire facility dedicated to Alzheimer's and dementia patients.

Hale said Gentiva deals with enough Alzheimer's patients that he believes such a facility "would be full fairly quickly."

Ahles said the 12 beds at Good Samaritan are often full.

"There's a need for more service for those folks," she said.

She had the opportunity to see an assisted living center in Coeur d' Alene set up specifically for dementia patients. It was designed to where wandering patients who leave their room would be led back to it.

There are a growing number of advancements in Alzheimer's care. An Oct. 10 Reuters news service

report said research shows that while their memories don't last, their mood lingers. Patients who were just shown a feel-good movie, felt happy long after they forgot about the details of the film. Cornish said she sees this firsthand when she takes her patients to family movies.

Emotional understanding

More caregivers are coming to the conclusion that appealing to their emotions and understanding their reality can be more effective than medication.

Cornish, for example, said her staff are trained to pretend they're old friends with the patient. That way the patient will feel more comfortable around them.

A 2010 New York Times report shed light on a program in Philadelphia that cares for patients by allowing them to do an activity they remember from their past. Since they often lose short-term memory, but retain much of their long-term memory, they often enjoy the things they did when they were younger.

At the Philadelphia program, this includes arranging flowers, setting up a tackle box or filling photo albums.

This improves their wellbeing by making them happier and more active, the report said. These patients also show fewer behavior problems like repetitive questioning.

Ahles has seen this shift in treatment with her line of work. Instead of trying to force the patient into our world, caregivers now do something differently.

"You go to their reality," she said.

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