

County learns about dementia

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JEFFERSON — Jefferson County government workers on Wednesday became the first in Wisconsin to undergo training to be declared a dementia-friendly community.

Dozens of Jefferson County department heads and other employees gathered at the courthouse for the afternoon kickoff event, featuring guest speakers Rep. John Jagler and Tom Hlavacek, executive director of the Southeastern Wisconsin Alzheimer's Association, along with subsequent training sessions.

"Today, we begin a process of becoming a leader in the state," Jefferson County Board of Supervisors Chairperson Jim Schroeder said.

"We're going to be one of the first counties in Wisconsin that commits itself to becoming dementia-friendly. This is important. We all know a family that has been, is or will be touched by dementia. So, by committing to providing our services here at the courthouse and other facilities in a dementia-friendly manner, and also by getting the word out in our communities, we're really making a difference."

Helping lead the event were Jefferson County Human Services Aging and Disability Resource Division manager Sue Torum and dementia care specialist Cathy Kehoe.

"What is a dementia-friendly community and why is it important for us, as county government to embrace it?" Torum asked. "Because, most of the people with dementia live in their own homes in their home communities (and) 30 percent of those living in their own homes live alone. Those are the people who come to the courthouse, who we often get calls on, or are here at the Veterans Service Office looking for help, but they can't say what the help is. Those are the folks that perhaps the sheriff's office is getting a call about, saying they're walking down the middle of the road in the middle of winter without adequate clothing on."

Some employees know who to call, Torum said. However, most do not.



PURPLE ANGEL

She said that the goal is to build a culture of change, one where not just department supervisors recognize to call Human Services or dementia care specialists, but a culture where all employees can recognize, first and foremost, that there is a problem and the person needs help.

“A flourishing community seeks to honor, value and include all of its members in a common life,” Torum said, quoting the Rev. John McFadden of the Fox Valley Memory Project. “It actively seeks creative improvements in a shared life because it understands that meeting the needs of the most vulnerable and dependent members cannot be separated from its own.”

“People with dementia have the right to live at home,” Torum continued in her own words. “The right to be served by community services in a warm, welcoming, compassionate manner, one that supports and understands, that can recognize what dementia is and it’s a better community for all of us.”

“Dementia” is not a diagnosis in and of itself, Kehoe explained. It is an “umbrella term.”

“It’s kind of like the term flowers and then you have daisies,” she said. “Alzheimer’s is the most prevalent kind of dementia. It’s somewhere between 60 and 80 percent of all dementia cases.”

A fact sheet from the Alzheimer’s Association lists other kinds of dementia, including mild cognitive impairment (MCI), vascular dementia (VaD), mixed dementia, dementia with Lewy bodies (DLB) and frontotemporal dementia (FTD).

All types of dementia involve mental decline that occurred from a higher level; is severe enough to interfere with usual activities and daily life; affects more than one of the four core mental abilities: language, visuospatial function, recent memory and executive function.

Jagler and Hlavacek also addressed attendees.

“It’s a privilege and an honor to be here. I am very passionate about this topic,” Jagler said. “I never in a million years thought that this topic, this issue, would gather up and encompass all my time for a couple of months. It was something I didn’t know a lot about. I’ve been blessed to not have anybody in my immediate family have Alzheimer’s or (other types of) dementia, but I was asked to serve on the taskforce (on mental health) and it became a passion of mine this past session.”

The taskforces are made up of equal members of Democrats and Republicans and there is a co-chair from each party Jagler said.

“We traveled the state, heard much of the same stories, much of the same message,” he said. “Much of it was depressing, to be honest with you. It’s not a happy topic. It’s a topic that needs to be addressed. It’s a topic that is overwhelming. I talk to Cathy Kehoe about it and I say, ‘this is overwhelming and depressing; how can I help even a little? What can we do?’”

It's a tough thing in the community, Jagler said. While dementia does not directly affect him, his daughter, Grace, has special needs and he sees how she is treated differently.

"I know that (people with special needs) get treated different by some, and it's not that they want to treat them different, but they're scared, nervous or they don't know," the representative said. "So the training that can be done in the business community, just on customer service, just making it easy to recognize, 'there's no reason to be scared of this person, this person needs help.' That's the connection I have with Alzheimer's and dementia. It's not direct, but to me, it's a lot of the same thing. It's being compassionate and not being scared."

Jagler said that, in Madison, it is important to get dementia "on the radar screen" of the 99 members of the state Assembly, because it opens the door for further legislation and funding dollars to flow.

"Right now, if anything came from these taskforce sessions on mental health and on dementia, it's that the legislators are aware," he explained. "There are a lot of people like me who it hasn't had an immediate effect yet, who hasn't been touched by it yet."

He said that in the last legislative session, eight bills were passed in the Assembly.

"I got criticized by my speaker. He said, 'you said the bills that we have out of the taskforce are just nibbling around the edges.' I said, 'Well, Mr. Speaker, they are,'" Jagler explained. "I know that there's more that needs to be done, more dollars that are necessary. These bills are great and I'm proud to work on them, but they do just nibble around the edge. Nibbling right now leads to a bigger bite later, I hope, for my colleagues when they see this."

What Jefferson County is doing is amazing, he said.

"I've got to tell you, when I tell representatives from around the state, or I talk to other counties, similar folks doing what (Jefferson County) is doing in a different county — Jefferson County is a star," Jagler said.

"It's a rock star on a lot of different topics. On what you're doing, how you're working together — it is the envy of a lot of county departments. What (Jefferson County) is doing is being recognized and being modeled as (other counties) hope to achieve what (Jefferson County) is doing already. This is a big first step."

Hlavacek agreed.

"What you're doing in Jefferson County, compared to what they passed on the state Legislature, would be (Jefferson County) is the Green Bay Packers and (Madison) is a high school football team," Hlavacek said. "Honest to God, because you're doing a heck of a lot more in this county than many counties around the state."

Currently, there are approximately 120,000 people in Wisconsin who suffer from some form of dementia and 5.3 million on the national level, according to Hlavacek.

“How do we know those numbers? We don’t know those numbers by looking at people’s medical records, because only half are diagnosed,” he said. “We know from epidemiological studies or disease studies. Over half (of those suffering from dementia) are undiagnosed or misdiagnosed and are just out there in the community.”

Of the 50 percent of individuals diagnosed with a form of dementia, approximately 40 percent are not told their diagnosis and neither are their family members.

“That kind of surprises you,” Hlavacek said. “Well, there’s a lot of doctors that have this belief: ‘Well, there’s nothing you can do about Alzheimer’s. It’s only going to make it worse if we tell the people about it.’ So they don’t tell people about it.

“Now, what does that do? That means they’re automatically cut off from being able to do planning in their lives, to be able to think about advance directives, being able to get connected up to resources — so it’s a travesty and we’re trying to change all that.

“But in the meantime, if you think about it, you’ve got half the people not diagnosed and half of them that are diagnosed not knowing,” he continued. “You have people living in very isolated circumstances. Is it a surprise that the most common way we find out about people with dementia in our communities is through crisis?”

So the question becomes, he said, what do you do if you come across someone with dementia in a crisis situation?

Kehoe addressed several methods during the training session, including fully introducing yourself; standing face-to-face; speaking slowly and clearly while avoiding speaking to the individual as if he or she were a child; asking simple yes or no questions; using gestures to indicate an action; and making sure to listen carefully to what the person in crisis is saying and doing, repeating back to him or her what you heard and, if he or she changes what he or she is saying, going with it and not correcting them.

“(People who have dementia) have a different reality than we do because they perceive the world differently than we do and it’s not really so much something to be afraid of as it is something to understand,” Kehoe said.

“So this training we’re having is helping everybody to understand what it’s like to have dementia and also to help that person and be able to communicate with them in a meaningful way.”