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Dealing with dementia

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Dementia affects not only the person, but their family, peers, friends, faith community and support systems.

Bluestem Communities hosted a “Innovations in Living with Dementia” community forum Wednesday at Hesston Mennonite Church. Teepa Snow, a graduate of Duke University who is an occupational therapist and dementia education specialist, spoke about how faith communities can help those living with dementia.

“Having a little dementia is like being a little pregnant. There is no such thing. You are or you aren’t, you do or you don’t, and once you do, you know you’re on a journey,” Snow said.

Snow shared with the audience how people can notice the onset of dementia, get and give help, be there for those with dementia and their caregivers and find joy through the hard times. Using audience interaction and roleplaying, she demonstrated how caregivers, family and friends often don’t know how to react to a person with dementia.

Only 20 percent of those who get dementia have it caught in the early stages, according to Snow. Subtle, inconsistent signs make it difficult to diagnose. 10 percent of people age 65 have dementia; by the time they are 85 years old, 50 percent will have some form of dementia. Those who have dementia will struggle with it for eight to 12 years, on average. At the end of dementia, patients can have one-third of the brain size of a normal adult.

“It’s time to stop acting like this isn’t going to happen to those we care about and start getting serious about this stuff,” Snow said.

According to the National Institute on Aging, there are several major types of dementia, including Alzheimer's, Lewy body dementia, vascular dementia and frontotemporal disorders.

"This group is very different...it's not like a medical illness," Snow said.

People find it hard to spend time with dementia patients, who are not "themselves" any more. Friends and family may withdraw from the person. The person with dementia can often sense that they are changing and that something is wrong. Out of fear, they cling to those they know best, wanting to spend an ever-increasing amount of time with them.

The Alzheimer's Association notes that 15 million caregivers provided 18 billion hours of unpaid care in 2015. Caregivers give of their time out of love, but may reach a point where they find themselves stretched thin. When caregivers realize they need a break from the stress, it can be challenging to take the needed break that can cause confusion for the dementia patient.

Stress, sleep deprivation and loneliness are common for caregivers, while dementia patients suffer hallucinations, sleeplessness, delusional thinking and are prone to falls.

Snow noted it is easier to aid caregivers by not just asking how you can help, but by asking which of a few specific actions (such as sending a card or taking a meal) the caregiver would like for you to do to support them.

Dementia patients lose touch with language, Snow explained, not only by finding it hard to say words when they want to, but also by having difficulty absorbing the meaning of words spoken to them. Snow suggested adding gestures to help convey meaning.

Snow said leaders need to know how to deal with those suffering from dementia and their caregivers, who can find it hard to explain what they are going through. She is a proponent of churches having classes to educate their members about dementia so they know what to expect.

“Should a faith community know this stuff? Yes. This is where I come for comfort. If you don’t know anything, then you can’t comfort me,” Snow said. “We’re going to deal with this better as a community than as individuals.”