

Caregivers learn about Alzheimer's, preparing for death

By Frances K. Foster

Staff reporter

Participants in the Sheridan Senior Center's conference for family and professional caregivers held at Best Western Sheridan Center on Monday learned techniques for working with Alzheimer's patients and the importance of "managing" for expected deaths, i.e., the death of someone who suffers from a fatal disease or other life-threatening condition.

Jo Huey — a trained Alzheimer's specialist — provided a list of 10 "musts" for caregivers working with Alzheimer's sufferers, the most important being, "Never argue — always agree."

Caregivers cannot win arguments with those suffering from Alzheimer's, because the patient's brain cells are dying in reverse order, i.e., they forget the most recent events and conversations first and keep the most distant memories until the late stages of the disease, she said.

Nothing can be done to stop the cells from being "erased" or reverse the damage already done, so arguing



Jo Huey
Alzheimer's Specialist



Thomas Niethammer
Sheridan Internist

only creates frustration for both caregiver and patient, Huey said. No number of reminders will make a difference, she added.

But Huey does not promote lying to the patient. One of the most common challenges of the caregiver is when the patient is looking for someone who's dead. What can the caregiver do? she asked.

If the patient is told the person is dead, he will experience the sadness of the news all over again

as if he'd never known it. And he will forget the news again and continue asking about the dead person.

Huey suggested what she calls the "new truth" when the Alzheimer's patient asks about a dead person: "I haven't seen him today." Then change the subject as soon as possible to keep the patient from thinking about the deceased, she recommended.

Another common complaint of the Alzheimer's patient is, "I want to go home." No matter where the patient currently resides — in his own home, at a nursing home, or in a hospital — the caregiver should reply, "You are home." In the sense that the patient resides in a place, that is his home, Huey explained.

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“Everybody in this room is going to die. That’s a given,” Dr. Thomas Niethammer — a Sheridan internist — opened his presentation with.

Therefore, “You should manage as best as you can for you and your family” for that time by making sure other family members, doctors, and friends know exactly what kind of medical care and procedures are wanted — or not wanted, he said.

Alzheimer’s is a terminal disease; it cannot be cured, and it will appear on the death certificate when the patient dies, he noted.

In the last stages of the disease, the patient may be unable to eat or drink. Most medical ethicists agree that, especially for patients whose cognitive capabilities are gone, allowing the person to die

from starvation and dehydration is considered “very ethical” as long as pain and discomfort are controlled.

“It’s not killing the patient. It’s letting the disease take its course,” he said.

“That really sounds hard,” especially for a family caregiver, but if early enough in the disease, the patient has provided written directions that he does not want his life “extended,” then it is the caregiver’s responsibility to make sure those directions are carried out, he said.

Infections are also common causes of death for Alzheimer’s patients, Niethammer said, and it is difficult to decide “at what point whether to treat the patient with antibiotics or to stop,” he said.

Also, “At what point do we rush him to the hospital?” he asked. Again, if the patient has

requested “no resuscitation,” then these decisions — although still emotional — are easier to make.

If a person chooses to wear a Comfort One bracelet — which requests no “extraordinary medical care” — then emergency medical technicians and emergency room doctors with no access to the person’s medical history know that the patient’s wishes are to let him die, Niethammer said.

If the patient has previously made his wishes known, that does not mean he has to suffer. Morphine can relieve his pain until he dies from his disease, Niethammer said. “Morphine doesn’t kill people — the disease will,” he said.

“Give them (a loved one) permission to die,” Niethammer advised.

It is therapeutic for both caregiver and patient for their last shared words to be, “You’ve been a great dad. You can go now.”