Families Need Dementia Facts

SALT LAKE CITY — Families often don't know what to expect when a loved one has advanced dementia, says medical director Dr. Aida Wen, CMD, speaking at AMDA's Annual Symposium.

"Families really need to know what to expect over the last months and weeks of their loved one's life," Dr. Wen said. Tube feeding is one issue that requires discussion. "Patients with advanced dementia often have difficulty eating. Families need to know that tube feeding isn't a free ride and doesn't prolong life. It also deprives people of the enjoyment of tasting food," she explained.

The family should be encouraged to work with staff to offer these residents foods they enjoy and to respect their wishes if they don't want to eat. "It is useful to urge families to come and feed their loved one or hire someone to do it," Dr. Wen noted. Individuals with dementia most commonly die from infection, so "we need to discuss with families how we will prevent infections and what decisions will be necessary if one develops." She added, "We have to communicate effectively with families so they have realistic expectations about treatment and prognoses."

Staff aren't the only ones who need to understand pain assessment. Families also can help recognize and assess pain in their loved ones. This can lead to more prompt pain treatment and help families understand pharmacologic and nonpharmacologic approaches to pain management.

The medical director needs to help educate families about hospice and help families determine when hospice care might be necessary. The physician leader also should work with families to ensure that they get the help they need—such as bereavement counseling.

—Joanne Kaldy

'Namaste' Care Honors the Spirit Within Advanced-Dementia Patients

BY JOANNE KALDY

SALT LAKE CITY — "There is no excuse for having a poor dementia care program," said author and geriatric consultant Joyce Simard, MSW. While developing programming for residents with advanced dementia can be challenging, Ms. Simard has developed an initiative called "Namaste" care that addresses the emotional and physical needs of these individuals and their caregivers and families. She discussed Namaste care during a session at AMDA's 2008 Annual Symposium.

Simply translated, Namaste is a Hindu term that means "to honor the spirit within." Simard observed, "I developed this program for those patients with no voice." She described these as individuals who "you see sitting in the hallways or their rooms. They are well groomed and cared for, but they are not engaged," she said.

Namaste engages these residents with "loving touch." A specially designated room is needed for the program, but it doesn't have to be the best or biggest in the facility. "It's about the program, not the prettiness of the space," Ms. Simard stated.

In a typical Namaste room, several residents are seated comfortably in lounge chairs wrapped in soft comforters or blankets. Soft music and the scent of lavender fill the air. Some residents clutch lifelike stuffed dogs or other animals; others wear favorite hats or other accessories.

"Everyone who comes into the Namaste room is touched in some way—even if it's just a handshake," Ms. Simard noted. More commonly, she added, participants are getting gentle manicures or hand massages with fragrant lotion or having their hair brushed lovingly. Pleasant sights and smells—such as flowers, baked goods, or fresh-cut grass—are designed to elicit positive memories and reactions.

COURTESY JOYCE SIMARD

Geriatric consultant Joyce Simard uses touch to comfort a resident shortly before her death.

While morning Namaste programs are filled with calm and comfort, the afternoon activities expand to sensory stimulation including a range of motion exercises and music that is bright and up-tempo. Sometimes, the music is live—featuring a volunteer or family member playing an instrument and/or singing. Families are encouraged to visit the Namaste room in the afternoon and to participate or assist in activities.

Ms. Simard stressed that the Namaste room isn't right for every person with dementia. "You can't have someone who is crying, screaming, or acting out," she said. It also is not a good match for individuals with terminal illnesses—such as cancer—who are still alert and cognitively intact.

However, anyone can receive Namaste services in their rooms or after hours with "Namaste a la carte," said Ms. Simard. This generally involves a mobile cart with lotions, lavender spray, and other items that can be used at any time day or night.

Namaste doesn't end with the daily activities. There are other elements of the program designed to protect residents' dignity and comfort and to acknowledge the bond that often exists between these individuals and staff. "We try to make sure that these residents don't die alone. When someone is dying, we let everyone know and always have someone by the bedside," said Ms. Simard. If a nursing assistant has a relationship with that person, others will try to take over his or her duties for care of other residents. The aide can then spend time with a "dying friend."

When the person dies, a blanket or quilt is draped over the body, and a staff member escorts the deceased to the hearse. Whenever possible, the person's bed remains empty—with a tribute such as flowers or pictures—for 24 hours. Staff and caregivers are encouraged to grieve and support each other when a resident passes.

While the Namaste program requires some investment—for staff time and items such as lounge chairs and stuffed animals—this cost is well worth the results, said Ms. Simard. "The program can help increase census and revenues. It presents an opportunity for another dementia unit and the ability to move residents into this program who no longer can benefit from other activities." Additionally, it might result in referrals of home-based patients by hospices.

As for staffing, Ms. Simard explained, "We often start by using existing staff and end up with an assigned person. You often can rationalize the staff time by reminding administrators and others that you also are taking several residents off the floor all day." Some of the best Namaste leaders are certified nursing assistants "who have been doing their jobs for a long time and are having trouble handling the physical work." Ms. Simard suggested, "You need someone with energy and enthusiasm to make the program work."

No study has documented the benefits of Namaste, Ms. Simard noted. She said that she is currently collecting data from the Minimum Data Sets to conduct research on clinical outcomes. She said she expects to see some impressive results because the program encourages better monitoring of problems such as falls or dehydration "because the residents are all in one room all day." Additionally, she noted that some facilities with Namaste have noticed fewer instances of agitation and behavioral problems in their demented residents.

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