

Enhancing the Quality of Life for Advanced Dementia Patients

Bon Secours NY Health System's Program Aims to Set New Standards

BY NADINE K. BAKER

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The Seniors Partaking of Oral Nourishment (SPOON) Program describes a new standard of compassionate, end-of-life care designed to enhance the quality of life of advanced dementia residents in nursing homes. SPOON also increases family awareness about the terminal nature of dementia, empowers family decision-making and improves satisfaction with care.

One of the primary reasons cited for the lack of attention paid to quality, end-of-life care is the fact that advanced dementia is rarely seen as a *terminal* illness. Because the length of survival for dementia patients can be several years, physicians and family members struggle to view someone with dementia as dying.

The SPOON Program brings a better quality of life for advanced dementia residents because they are better understood, the time spent with them in one-on-one relationships is increased, they

are able to experience the pleasure of tasting food, and the risk for restraints and infections due to tube feeding is sharply reduced.

The SPOON Program was created in response to a challenge identified by Paulette Sansone, Ph.D., LMSW, who was the director of social services at Schervier Nursing Care Center, Riverdale, N.Y., for many years. Today, she is the vice president of research and education for the Schervier Center for Research in Geriatric Care. Sansone understood the problem faced by many nursing homes with residents with advanced dementia: the inability to feed themselves. She received a grant from the Fan Fox & Leslie R. Samuels Foundation to help establish the program.

In centuries past, failure to feed oneself was recognized as the beginning of the end of life, and plans were made accordingly. With the advent of

more modern medicine in the past 20 years, physicians created a "solution" that, while it can be quite helpful for individuals with short-term feeding problems, has been a distressing resolution for terminally ill dementia residents. The solution is that doctors ordered the insertion of a gastrostomy feeding tube to enable these individuals to receive passive nourishment. Sadly, tube feeding in nursing homes has grown exponentially in recent decades due to physician, staff and family misconceptions about its benefits and harms. As a long-term solution, this method has many pitfalls; chief among them is that the individual's quality of life is severely compromised and a peaceful death is far less likely. That is because, in the late stages of dementia, the resident becomes totally dependent for care. At this juncture, physical and neurological changes increase, joints become rigid and contracted, infantile reflexes develop and the ability to feed oneself is lost.

The problem of using feeding tubes for advanced dementia residents is the tubes don't work as imagined. They don't prevent pressure sores, malnutrition or aspiration, and they don't improve quality of life or functional status. That's why it's an unworkable solution.

Indeed, scientific evidence has shown that feeding tubes often increase resident suffering as well as the burden of advanced dementia. They decrease quality of life, they remove the pleasure of tasting food, which is one of the few remaining "pleasures," they deprive residents of the socialization and companionship associated with mealtime and the nurturing associated with hand feeding.

Nurturing is what the mission of Bon Secours is all about. Specifically, the mission of Bon Secours New York Health System and Schervier is to "bring compassion to health care, and to be 'good help' to those in need, especially the dying." Feeding tubes for terminally ill nursing home residents is contrary to the spirit of the Bon Secours mission. That is why another solution had to be found.

We needed a compassionate solution to help these dying residents both live and die with dignity. Our current approach is simply hand-feeding these

Contact Information

For more information about this program, contact Paulette Sansone, Ph.D., vice president of the Schervier Center for Research in Geriatric Care, at (718) 432-1939 or paulette_sansone@bshsi.org.



Photo by Joshua Bright

Migdalia Arroyo volunteers at the Schervier Nursing Care Center, feeding residents Ruth Schoenbach, 85, left, and Stella Savino, 89.

residents one at a time. But that solution itself was problematic, because one individual might take an entire hour to hand-feed, whereas the staff-to-resident ratio is not one to one. There are not enough certified nursing assistants to hand-feed the residents who need that degree of assistance.

Indeed, to quote Everett Rogers in his book *Diffusion of Innovations*, “Getting a new idea adopted, even when it has obvious advantages, is often very difficult.”* That’s why we needed more than just our simple and great idea — we needed a way to carry it out and make it happen.

Our current approach is innovative because it doesn’t rely solely on paid staff. Instead, in some cases, it relies on “the kindness of strangers.” Some of our hand-feeders *are* strangers, but not all. All are volunteers. Some of our volunteers are non-clinical staff, family members, recent retirees who want to give back, and teenagers. No one is paid for feeding. But is this method sustainable?

The SPOON Program is a successful beginning. Finding and training volunteers is less of a problem than the frequency with which they are available to feed. We began by offering training to all staff about the issue itself — the terminal nature of dementia and the fact that feeding tubes don’t bring about an improved quality of life and death for these residents. In this regard, we trained 113 employees of all levels, including physicians.

Our goal was to recruit and train at least 20 volunteers and family members who were interested and willing to hand-feed safely, appropriately and patiently. We sent press releases to local newspapers seeking volunteers, and utilized our active volunteer program. To date, we have had six training

sessions for 62 volunteers, consisting of family members, employees and community volunteers.

Volunteer employees may feed a resident lunch during their workday (and afterwards, eat their own lunch at their desk). Others may wait until after work to feed a resident dinner. Some family members visit their loved one daily, and feeding them lunch and/or dinner is something they’re willing, indeed, happy to do. Retirees will often volunteer because it brings them pleasure to know they are making a qualitative difference in someone’s life.

The benefits of hand-feeding individuals who have advanced dementia are an improved quality of life and death, with a holistic focus on comfort and psychosocial and spiritual needs. ■

*Everett Rogers, *Diffusion of Innovations* (New York: The Free Press, 1995)1.



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The Mission

The mission of the Bon Secours New York Health System is to bring compassion to health care and to be “good help” to those in need. Bon Secours New York’s mission is carried out through the services and programs of Schervier Nursing Care Center; Burke at Schervier Short-Term Rehabilitation; Schervier Respite Care; Schervier Center for Alzheimer’s and Dementia Care; Schervier Home Health Care; Schervier Center for Research in Geriatric Care; the Schervier Apartments; Interfaith Caregivers; and Buena Ayuda Para Personas de Edad. Information about Schervier and Bon Secours New York Health System may be obtained at www.scherviercares.org.