

Mathew's Story

Matthew Wilk died on July 12, 2004. Matthew was:

- Husband of Celia, 56 years of marriage
- Father of Five
- Retired transformer specialist for General Electric for 35 years
- Living with dementia for the past 6 years

Matthew's last weeks could have been sad, they were not.

Matthew's last days could have been heartbreaking, they were not.

Matthew's last hours could have been, distressing, they were not.

Matthew's death could have been devastating, it was not.

Because of a new program, Namaste, implemented at the Vermont Veterans Home in Bennington Vermont Matthew Wilks last weeks and days were pain free and filled with the presence of others. His family was supported, and the staff caring for him felt valued. Matthew slipped away on a sunny afternoon with his wife at his side, the charge nurse and myself. His wife had just told a funny story about their life together and we all laughed as Matthew left us. He ended his difficult journey with Alzheimer's disease on the wings of laughter. In Matthew's honor then; the story of Namaste and how it can change the way residents with terminal dementia living in long-term care facilities can experience the "good death" we all seek.

Since the 1980's care for residents with Alzheimer's disease or a related dementia has improved with the emergence of Special Care Units (SCU's) for residents in nursing facilities with dementia who were at risk of elopement and whose behavior could not be managed elsewhere in the building. SCU's were secured and activities were designed for their unique population. Special training was provided for staff, medications were more appropriately prescribed and restraints began to disappear. Over the years, activities for residents with dementia have become the norm for nursing facilities. When a resident's dementia progressed and they could no longer actively engage in activities, activity professionals would make brief individual visits several times a week or the residents would be placed in a room where activities were taking place. Nursing would either put the resident to bed or place them around the nurses station where they could be observed. Residents in the advanced stage of dementia were kept clean, fed, and for the most part, pain free.

Some effort was made to involve hospice in end-of-life care for residents with Alzheimer's disease but with very little success. Hospice was and continues to be reluctant to accept a person with dementia. The Medicare Hospice Benefit requires a prognosis of six months of life that physicians have problems making. Hospice workers are also used to working with patients who can participate in end of life decisions. They are not quite sure how to relate to the patient with terminal dementia. Nursing facilities also feel that they are giving the best care possible and may resent hospice staff "intruding" in the care of *their* resident.

While most nursing facilities take very good physical care of residents with terminal dementia, the residents *quality of life*, their "personhood", that aspect of life that transcends the physical,

has been ignored. That is not and should not be acceptable. Namaste is a program that changes the way we care for people in this last stage of a dementing illness. Although originally my idea, the program has taken a life of its own thanks to a creative and committed staff. This little seed has blossomed in ways I never dreamed. And, the most exciting aspect of developing Namaste is that each week another good idea emerges; another way to reach our residents, support families and staff. Namaste is an ever changing, fluid dream come true.

The term Namaste means, "to honor the spirit within", a perfect title for a program and approach to care for people who can no longer speak for themselves, whose lives have been diminished by dementia. Namaste can be implemented as a "day program" where residents live throughout the building and are taken to the Namaste room. In the Bennington facility however, Namaste is located in one unit of the facility. We found it easier to care for terminal residents when they are grouped together. This has enabled our Namaste staff to "specialize" in end-of-life care and has helped to make this unit a peaceful place in a bustling building.

We found that to make a unit for Namaste we needed at a minimum a room for programming. This room needs to have a sink and refrigerator for snacks and beverages. Staff felt sunlight was important so a room with windows is a plus. The room needs to look as non-institutional as possible. Not having a great deal of money for renovations, staff became creative with furniture from Goodwill, donated plants, quilts, and other items that helped to create a warm home-like "living room". We also felt strongly that a private room for residents who are actively dying should be part of the unit. If the room is not being used for Namaste residents any resident in the facility who is actively dying is welcome to use it.

Matthew was moved to the Namaste unit several weeks before his death. He spent his days in the living room where other residents and a caring staff surrounded him. Matthew's days began with the sound of classical music wafting through the corridors. This peaceful awareness of the day's beginning is the responsibility of the nursing assistants. When staff assist residents for morning care and prepare them for breakfast, they turn on the sound system in the corridor. Namaste residents begin (and end) the day with beautiful music.

During the planning for Namaste, a great deal of time was spent discussing "comfort care". This term is usually applied to medical issues like DNR, tube feeding, or hospitalizations. We even discussed if weights or vitals were necessary. As Namaste "grew" staff began to view comfort care in a variety of ways. For instance clothing. Matthew could no longer ambulate so shoes were replaced with comfortable slipper sox. Belts were not used; soft sweat pants replaced harsher fabrics. Many of the men had shorts for the summer and after noticing how cold their skin became when their legs were not covered, shorts were eliminated. Staff realized that women did not need restrictive bras and dresses or pants were chosen for comfort. Families were informed why comfortable clothing were needed and helped by taking home or donating clothing no longer appropriate for this stage of life. The facility also helped by purchasing a large quantity of slipper socks in many sizes so they were always available.

After breakfast, Matthew was taken to the Namaste living room where more lively "wake-up" music was playing. He was greeted by the Namaste Program Specialist, taken from his wheelchair and placed in a comfortable lounge chair. A quilt was tucked around him and small pillows placed to ensure maximum comfort. The rehabilitation therapist had made an evaluation of how best to position Matthew so that he would not only be comfortable, but in a safe seating

situation.

With help from nursing assistants, Matthew was wheeled over to the sink and told by staff that he was going to be shaved so that when his wife Celia visited, he would be looking quite handsome for her. A wet, warm face cloth was placed around his face and it was gently washed. Warm shaving lotion was used to help orient Matthew to the shaving experience. Women had their faces washed and soft lotion applied. Hair was combed as they were told how beautiful they looked.

With grooming completed, Matthew was wheeled next to the window where he could feel the soft breeze. Matthew had always enjoyed the out of doors so this special spot became Matthew's place. Next to him was an over the bed table with pictures of his family and items of interest to him like golfing paraphernalia. During the morning activities he was gently awakened by the sound of a bird (stuffed realistic bird with genuine bird sounds), and conversation from the staff.

During the morning program, Matthew had his feet washed and he was given a foot and leg massage. When he was awake, Matthew was moved in front of a television set playing a nature video or was engaged by individual attention from staff. Matthew was not consuming enough calories during meals so the staff made sure he had high calorie snacks and beverages throughout the day. We knew that Matthew had a "sweet tooth" so he was given a hard lollypop to suck on. This brought smile to his face and gave him additional calories and the comfort of the sucking movement.

Lunch was served in the dining room while the Namaste Program Specialist did paperwork and had her lunch. Breaks for the Namaste staff are provided in the morning and afternoon by nursing assistants. We found that assigning one nursing assistant to be the "lead" for Namaste worked very well. He was responsible for helping to serve beverages, providing a break for the specialist and another pair of hands to provide special programming.

After lunch residents were toileted and either put to bed or taken to the living room. Staff evaluated each resident to determine if they needed to rest in bed during the day and if the morning or afternoon was more appropriate for them. Matthew was bathed using Comfort Care approaches. A bed bath was given when a shower or tub bath became uncomfortable.

The Namaste living room opened after lunch and again Matthew was warmly greeted. He was not placed in a lounge chair because his wife was coming to visit and wanted to be able to wheel his chair outside. To prepare for her visit, Matthew was told she would be visiting and a scarf with her favorite perfume scent was placed around his neck. Celia arrived to hugs from the staff. They told her about Matthew's morning and all the positives they could communicate. As his condition deteriorated, it was important for her to hear that he was "happy" and well cared for. Like so many spouses, Celia had cared for Matthew for many years and it was difficult to turn his care over to others.

Some days Celia wanted to take Matthew out of the living room and spend time alone with him, other days she needed to be with staff so she had someone to talk with and share stories of her life with her husband of so many years. Celia attended the facility support group and family lunches. The Dementia Program Director was available to talk with her when she needed someone, as was the charge nurse who made herself available whenever Celia had questions. The

Namaste staff were very affectionate and Celia had a healthy dose of hugs whenever she visited.

During the afternoon, Matthew had range-of-motion exercises provided by the specialist who was a trained rehabilitation aide. This not only provided Matthew with much needed exercise, but also rehabilitation therapy can help increase reimbursement. A variety of musical sounds such as rain stick, bells or wind chimes provided additional pleasant stimulation. Reminiscence items and soft animal figures were used during individual visits. Sometimes staff just held his hand and looked into his eyes. Matthew was loved and with his peaceful demeanor, we believe he felt it.

Namaste programming ended before the evening meal. Again Matthew was toileted and taken to the dining room. After dinner Matthew returned to the living room where a nursing assistant played music and visited with him until he was taken to bed. Depending on the alertness of residents after dinner, aides would put a musical video on, take residents outside, offer ice cream or just were "present" for the group.

Four days before his death, Matthew's condition deteriorated. The charge nurse and program director approached Celia to see if she would feel more comfortable moving Matthew to the Reagan Room; a private room named for Ronald Reagan who had recently died from Alzheimer's disease. She agreed and Matthew was moved. Personal pictures were moved to make the room look homey. Staff checked on Matthew several times each hour to assess his condition. He was kept comfortable with morphine and seemed very peaceful. The family was offered food and beverages and overnight accommodations in the guest room. When Matthew seemed to rally on the third day, his children returned to their homes in another state. It appeared that Matthew did not want to die with his children present for as soon as they all left his condition worsened. The Namaste staff then stepped in to provide support and comfort for Celia. She was never alone for the last hours of Matthew's life.

As a consultant, I am rarely with residents at the end of life so it was an honor for me to be visiting on July 12th and to witness Matthews's death. When the nursing assistant who had been staying with the couple was needed to help feed residents, I stayed with Celia. We both held Matthews hands and did our best to help him on this last journey. While not a nurse, I have been present at enough deaths to gently explain what was happening. Celia told Matthew how much she loved him and cherished the years they had together. She told him she was and would be fine and that he could leave with her love. The charge nurse walked in the room and realized that death was imminent. She stayed at our side. I realized that both the nurse and I were crying. How wonderful I thought that after over twenty years for me in long-term care and countless deaths for the nurse we were both moved to tears. Matthew would take a breath then stop and we would all think he had left us and then he would take another breath. Celia then told the comical story about their life together and off he went with happiness surrounding him. We hugged Celia and she said her final good-bye. Death usually ends the story but not in Namaste. The resident is "ours" until they leave the building and then their memory lingers.

Honoring the spirit within continues after the death. When Celia was ready, she left the room and the aides cleaned Matthew's body and dressed him in pajamas. Women would be dressed in a nightgown. All medical equipment was taken from the room and the bedside table arranged with his pictures, a live plant to symbolize life and a small flag to pay homage to his years of service in the military. Celia then sat with him until the undertaker arrived. She left the room while an

aide helped put his body in the gurney. An American flag was placed over Matthew and he left us but not alone. Accompanying Matthew and Celia were the charge nurse, a nursing assistant and Namaste Specialist. Everyone touched the gurney and accompanied Matthew to the hearse. A short poem was read and everyone waved as Matthew was slowly driven away.

Celia remarked later that the experience of his death was beautiful, even peaceful. She was so surprised that although sad, she felt honored that staff was with her and shared the final moments. Accompanying him to the hearse was a closure for her, and she had an overwhelming feeling of peace. She said, "I'm glad I stayed to the end", "I would not have wanted to miss this last part of our journey".

After Matthew's death a silk rose was placed on his bed and the bedside table became a memorial of his life. Staff was thanked for their part in helping to make Matthew's death a "good death" and a memorial service was held later in the week.

As a postscript to Matthews' story, his wife and friends collected money to purchase a double bed for the Reagan Room so that spouses can lie next to each other if they choose. A lounge chair was purchased as Celia thought she would have been more comfortable with one. And so the story of Namaste told through the life and death of Matthew Wilk ends... or does it? Honoring the spirit within until and after death has touched all who are associated with Namaste. And so it will continue to grow to teach us about living and dying and hopefully will become the standard for long-term care providers.

Teach me to die
Hold on to my hand
I have so many questions I don't understand
Teach me to die
Give me all you can give
When you teach me to die
I will teach you to live