

*SILENT AND INVISIBLE; NURSING HOME RESIDENTS WITH ADVANCED DEMENTIA*

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WITH ADVANCED DEMENTIA**

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**Abstract:** The Namaste Care Program is designed to provide meaningful activities through therapeutic touch, music and life review to nursing home residents with advanced dementia. This program has improved resident care, staff and family satisfaction while increasing census. Namaste Care is easy to initiate and does not require additional staff or expensive supplies. The experience of one long-term care company EPOCH Senior Living of Waltham Massachusetts USA which offers Namaste Care in their skilled nursing facilities is explained. Management has concluded that program has been an important addition to the services they provide for residents and their families from both a business prospective and a quality of care standpoint.

**Key words:** Advanced dementia, Alzheimer's disease, terminal care.

Elizabeth is 84 years old. She has lived with Alzheimer's disease (AD) for the past eight years. She no longer walks, sometimes she makes sounds but most of her day is spent in bed; she becomes invisible. John has an irreversible dementia and is "parked" in front of the nurse's station for hours at a time. He occasionally cries out but no one can understand why. If he cannot be calmed, he is put back in his room; he becomes invisible. Emma, Julia and Harry all have been diagnosed with AD and are unable to actively participate in any of the activity programs offered. They are taken to a "day room" where they stare blankly at a television set; they are quiet and become invisible as staff scurry to assist the more vocal residents.

Residents like these are typical of thousands of nursing home residents with advanced dementia who are well cared for medically; given medication, vitals taken; they are groomed, changed, fed and bathed. They are the silent ones; easy to overlook as they are not vocal. As healthcare professionals, we should be asking, are we doing enough for these silent residents? Is this quality of life? Are we meeting their spiritual and social needs? Are we providing meaningful activities for the person with advanced dementia? Who is listening to their silent cries?

When first diagnosed, many people with early AD are vocal, they become fighters. They have found their voice individually "Speak up! Speak Out! Today!" (1) and collectively in support groups for people with early dementia. (2). They shout to anyone and everyone to listen to them. "I am still here, do not ignore me". "We need more; money for research, community based services and we want it now. Listen to us!"

As their disease continues its relentless journey, their voices begin to fade and families take over the fight. Families have become increasingly vocal about demanding good dementia care. They have lobbied regulators for tougher standards for dementia care and staff training. Families want to know that the staff can take care of their loved ones physical needs; they want staff to treat them as individuals. Staff members are

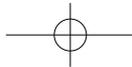
expected to know residents likes and dislikes and what approaches work best with them.

Families now have choices as the majority of nursing facilities offer some type of dementia program because the number of residents with dementia has increased in both assisted living and nursing facilities. Census drives the long-term care industry so it is a good business decision to offer a quality dementia program.

The voices of families and strong lobbying from the Alzheimer's Association have resulted in a change in the way state and federal surveyors inspect long-term care facilities. They focus on the individual resident. Tom Kitwood's (3) person-directed therapy has been incorporated into the survey process (4) as has the work of advocates for culture change who advocate for returning control and decision making to the residents and their caregivers (5). Surveyors do not just review documentation and medical issues; they are asking staff members about the resident as an individual. Person-directed approaches are now the expectation of regulators even for the resident with advanced dementia who is unable or has difficulty communicating. Staff members are expected to know the residents histories, what they like and dislike. Care plans are looked at by surveyors to see if they reflect the individual. Surveyors, family members and organizations such as the Alzheimer's Association have become the voice for people in the middle stage of a dementing illness.

Eventually however, the person with AD reaches the advanced stage of the disease. Their voices become increasingly silent. Many families are exhausted, and their voices also began to fade. Some families move on, visiting less, as they see little benefit in visiting with someone who does not even recognize them. Grandchildren and the residents "old" friends visit infrequently or not at all. They simply do not know what to do during a visit with a person who has little or no response to their questions or their attempts to have a conversation. And the losses for the resident with advanced





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dementia and their families continue to mount.

Often residents with advanced dementia are moved from the Special Care Unit (SCU) to another area of the facility. They are no longer ambulatory so the need for a secured unit is no longer a concern. Activity programs on a dementia unit are usually designed for the resident who can still respond to programming so transferring a resident who can no longer respond to another unit is not a loss for the resident from an activity perspective. Moving from the SCU is difficult for the resident as they are now cared for by new staff who may not know their idiosyncrasies. Families lose contact with staff members who know them and provide a measure of comfort. With fewer family visits and a resident who can not communicate with staff in a meaningful way, residents with advanced dementia become the voiceless ones.

It is time for healthcare professionals to become the voice for people with advanced dementia and perhaps get a little (or a lot) angry about the lack of attention they are given. It is time for healthcare providers to realize this: quality of life does not mean that just a person's physical needs should be met. Quality of life involves being lovingly touched, and not just during care. People with advanced dementia need to be in the presence of others, not isolated in their rooms or in a day room. People with advanced dementia deserve to have someone continue to communicate with them even if it is just making eye contact and speaking through their hearts. Special programs must be developed for the person with advanced dementia, so that they continue to live with quality to their lives until they take their last breath.

The Namaste Care Program (6) was developed to help give a "voice" to nursing home residents with advanced dementia. Namaste is a Hindu word that means "to honor the spirit within" which is the primary goal of the program; to honor each resident for their unique personhood, who they were and who they are. Each resident's spirit is nurtured with meaningful activities in a variety of ways such as touch, music, reading, aroma therapy and having someone present for them during most of the day. Namaste Care is offered in pleasant surroundings with a room dedicated to the program. Residents with advanced dementia are no longer left isolated in their rooms or in corridors; they are with other residents; in the presence of others. In facilities where Namaste Care has been implemented, the term "bed bound" is almost non-existent.

Namaste Care can be offered without adding staff and with a minimal amount of expense. The process begins with an assessment of the number of residents who would benefit from the program. Activity professionals and nursing staff can usually give a quick estimate of how many residents are in the advanced stage of a dementing illness and may be appropriate for Namaste Care. Residents who should be considered for Namaste Care usually meet the following criteria:

- Diagnosis of an irreversible dementia
- Mini-Mental State Exam score from 0-7
- Inability to participate in scheduled activity programs

- Non-ambulatory
- Difficulty with communication
- Total care with Activities of Daily Living

When the assessment has been completed, and a decision has been made by administration to proceed with the program, the next steps include educating and selecting staff, designating a room for the program, purchasing supplies and marketing the program both internally and externally.

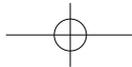
Educating staff is an important step in the implementation process. When staff members feel included in the design of the program and in the selection of residents, they feel that their input is valuable. The educational in-service includes the following:

- Overview of Alzheimer's disease
  - History of the disease
  - What is known about possible causes and cures
  - Prevention techniques
  - Symptoms
  - Medications
  - Impact on families
- Review of the burdens and benefits of medical intervention for people with advanced dementia (7)
  - Cardiopulmonary resuscitation
  - Tube feeding
  - Hospitalization
  - Treatment of infection
- Overview of the Namaste Care Program
- Questions

At the end of the educational program, staff members are asked who they think would benefit from Namaste Care. It's often surprising to administration that staff members offer names of residents that were not on the initial assessment list and staff members are pleased that they were asked for their input. Staff members are also informed that if they would like to apply for the Namaste Carer positions, they should notify their supervisor. When staff members feel that they are valued, that their opinion is important and that they have an opportunity to lead the program, their support helps to make Namaste Care successful. This educational program is also offered to residents and families. Members of the Resident Council and families are either invited to attend in-services along with facility staff or a special program is scheduled for them.

Qualifications for Namaste Carers are simple; the person must have a passion for this type of work. The majority of Namaste Carers are nursing assistants because of the need to have a qualified person feed and transfer residents safely. Occasionally someone who is a massage therapist or has another background is hired. In these instances, the carer may have to take additional training to provide personal care. Several Namaste Carers are selected and trained to ensure that the program runs seven days a week and covers staff vacations and illnesses. In some cases, the position is shared between





### *SILENT AND INVISIBLE; NURSING HOME RESIDENTS WITH ADVANCED DEMENTIA*

two lead carers with one scheduled for three days a week and the other four. Other programs have one lead person and the other days are filled from a pool of trained staff. Most facilities have found that they do not have to hire additional staff and assign one person for the morning and afternoon shift to assume responsibility for the program. After providing morning care and assisting with breakfast, one nursing assistant becomes the Namaste Carer and opens the Namaste Care Room. Supervision for the program is usually provided by the charge nurse on the unit where the program is located.

The Namaste Care Program needs a room dedicated to the program. The best possible situation is when the room can be totally dedicated to the program. The room can then be secured when staff is not present, supplies are safe and the special decorations are not disturbed. The ideal situation is for the room to have a sink and windows for natural light. This is the ideal, and in many facilities where space is limited, it is not possible to have a room dedicated to the program. Some programs have started temporarily in an empty resident room; others use a room that is also designated for dining or activities. In these cases storage of Namaste Care supplies and the décor must take into account that items may be disturbed. For instance, in a room dedicated to the program, live plants are used. In a room where residents have access to the space, they may decide to eat the plants or over water them so the use of silk plants is recommended.

Collecting supplies is necessary before the program can begin. Most Namaste Care supplies are those that are routinely supplied for resident care such as the following:

- Glycerin swab sticks
- Toothette oral swabs
- Q tips
- Lip gloss
- Safety razors
- Shaving lotion
- Basins
- Soap
- Gloves
- Disposable hand wipes
- Hand washing lotion
- Unscented body lotions
- Face cream
- Nail care items
- Towels, facecloths, blankets, quilts, pillows
- Large plastic bags for clean and soiled laundry

Each resident who attends Namaste Care is provided with a medium size plastic bag that can be tied or zipped closed. The residents name is marked on their bag for identification purposes. Bags contains a comb and/or hair brush, nail clippers and nail files, and personal items such as lipstick and hair ornaments for the ladies and a favorite shaving lotion for the male resident. Residents also have their own individual quilt or blanket in a larger marked bag.

Activity supplies for the program are minimal as Namaste Carers are very creative and use seasonal items that are free like lilacs and other flowers, leaves, freshly cut grass, fir tree clippings etc.

Activity supplies include the following:

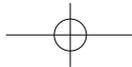
- Aromatherapy diffuser
- Essential oils, especially lavender
- Stuffed realistic animals such as birds that make real bird sounds and larger animals that can be held like dogs, cats and rabbits. Many residents are comforted by having a “pet” on their lap.
- Large screen television and CD player
- Nature videos and music CD’s
- Sensory material, lace, velvet, cashmere
- Antique items, kitchen implements, toys, tools
- Musical items, wind chimes, rain sticks, drums, singing bowls
- Humorous items, puppets, funny glasses, circus wigs
- Reading material, including spiritual or religious books and poetry

A typical day begins with the nursing staff providing morning care and assisting with breakfast. The majority of residents with advanced dementia do not feed themselves so this is a time consuming task. When breakfast is completed, residents are groomed and taken to the Namaste Care room. The room is prepared for the residents by lowering the lights, playing soothing music; making the room smell fragrant with the scent of lavender and checking to make sure all supplies are available. The residents are never left alone in the room so it is imperative that all preparations are completed before the room is “officially” opened.

Residents are taken to the Namaste Care room by staff members. The Namaste Carer greets each resident by name and with a touch, hug or handshake, whatever is appropriate for that particular resident. If the resident is not in a lounge chair, the resident is transferred from a wheelchair to a lounge chair usually by the Namaste Carer and one nursing assistant. In a few cases, a lift must be used for a patient who is heavy or unable to help with the transfer. In these cases, the lift is taken to the resident’s room and they arrive in the Namaste Room already in a lounge chair. Each resident has a quilt or blanket tucked around them. It appears that much like swaddling an infant, the security and warmth of having a blanket wrapped around them is comforting. Each resident who can safely suck on a lollipop is given a small one. This provides the pleasure of a sweet and helps to moisten the mouth.

After the majority of the residents are in the Namaste Room, the carer begins the day by gently washing each residents face, hands and arms and applying lotion. This is all done in an unhurried manner and with the carer talking to the resident. Carers know the past history of each resident so the conversation is individualized. When all resident have been washed and lotion has been applied, the carer may offer a





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number of other meaningful activities such as the following:

- Taking an item that reflects the season like lilacs in the spring, summer flowers, colorful autumn leaves in the fall and cinnamon sticks or a branch of a fir tree in the winter. One enterprising carer brought a snowball in much to the delight of the residents!
- Using a small stuffed bird with a realist bird call to remind residents that it is morning
- Reading special material to individual residents like well known poetry or religious prayers
- Providing nourishments such as puddings, ice cream and other easy to swallow and high caloric food.
- Offering liquid often to help with hydration. Some carers use plastic cups with tops that have an opening for a straw similar to what is provided in fast food restaurant. Each cup is marked with the residents name and placed near them. This makes it easy for the carer to offer “sips” many times during the day
- Brushing residents hair in a slow and pleasurable manner
- Shaving men the “old fashioned” way with a warm moist towel, shaving cream and a favorite after shave lotion. Often the shaving ends with the carer telling the resident how handsome he looks and offering a kiss on their cheek.

Thirty minutes before lunch arrives, nursing assistants begin to take residents to the dining room. When all residents have left the room, the carer tidies up, prepares for the afternoon and takes the soiled linen out of the room. If the room is dedicated to Namaste Care, the room is then locked and the carer leaves for their lunch.

After lunch some of the residents are taken to their room and changed and put to bed to rest. They are taken back to the Namaste Care room after an hour ‘nap’. The majority of residents are changed in their rooms and taken directly back to the Namaste Care room. The afternoon program is somewhat different from the morning program as the number of residents in the room is usually smaller than in the morning. If a large television is available residents might be grouped around it while a nature video is playing. The carer might take one resident at a time and wash and apply lotion their feet and legs, once again provided in an unhurried way with the carer talking to the resident during the process. Carers are taught that the process is more important than the task.

Afternoons are when the majority of families visit. Often they do not know what to do during visits when their loved one is unresponsive. In Namaste Care, however, visitors are given food and drinks to offer their loved ones or provided lotion so that they can massage hands and arms. One family member liked to braid her mother’s long hair. She was assured by the Namaste Carer that her mother loved this and that the carer could not do it as well as the daughter. The daughter then felt that her visits were more meaningful and that she could still do something for her mother that was special.

Music is an important aspect of Namaste Care. The type of

music played reflects the time of day and residents routine. When they arrive in the morning a soothing classical piece or nature sounds are playing. Before lunch the music changes to a livelier beat to help stimulate residents for lunch. After lunch lullaby or some other quieting selection plays so they can rest. Mid afternoon the music becomes more up tempo so that residents are more wakeful for family visits.

During the day, residents may leave the Namaste Care room for a bath, or for other personal care. If the resident is scheduled for a bath, they may be taken to the Namaste Care room in their robe and slippers. When the nursing assistant has taken care of the other residents in his or her assignment, they are free to give a relaxing bath to individual residents. The Namaste Care room door is usually closed to provide a quiet atmosphere but a sign on the door welcomes anyone to enter.

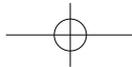
Namaste Carers understand that residents may sleep through most of the day as this is normal behavior for someone with advanced dementia. The carers, however, continue to talk to residents and provide activities. Residents who do not want to be disturbed will show their displeasure and their “non-verbal” communication is always honored.

Before the dinner meal, residents are taken back to their rooms and changed and taken to the dining room. The Namaste Carer then cleans the room and prepares for the next day. Paperwork is completed as required by regulations or facility standards. Often attendance is noted and food and liquid intake is documented.

One company, EPOCH Senior Living based in Waltham Massachusetts in the United States has responded to the special needs of their residents with advanced dementia. They have chosen to implement Namaste Care in their skilled nursing facilities. EPOCH management has found that Namaste Care benefits their residents, families and staff (8). After implementing Namaste Care, residents are calmer and some, who previously had not been communicating, are now making sounds or using a few words. Others are making eye contact and smiling, and hydration has increased as residents are receiving more liquids throughout the day. Families report that they feel less of a burden when they are visiting their loved one in the Namaste Care room. Seeing their loved one comfortably seated in a reclining lounge, the aroma of lavender filling the room, soothing music playing and with other residents around them is easier for families than finding their loved one in their room alone.

Staff state that they are less frustrated caring for residents with advanced dementia because of Namaste Care. Now they have a place to take them after breakfast where they will be watched over and are comfortable. It bothered them that residents who were alert and oriented or had moderate dementia and could still enjoy activities and had programs to attend after breakfast. Residents with advanced dementia would not benefit from these programs so staff had few options for where to place residents after breakfast; in their rooms alone, in a day room, or in the corridor often near the nurse’s station. The Namaste





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Care Program gave staff a special place to take residents that offered meaningful activities specifically designed for them. The program is offered throughout the day and is a seven days a week program. The result is that for most of every day, residents with advanced dementia have a special program designed specifically to meet their unique needs.

The impact of Namaste Care is immediate; the change is amazing. The first day it is put into operation, the dementia unit became noticeably quieter and more peaceful. Everyone notices, staff, families, visitors, prospective resident families touring the building. In one facility, a maintenance person had been hired to work on the security system. He was a specialist in securing dementia units so he was very familiar with the dementia care environments. At the end of the job he remarked that he could not believe this wing was a dementia unit as it was so peaceful.

Administrators and Director of Nurses were not only pleased with positive comments from family members and staff, but many found state surveyors praising the program. Surveyors had never seen a program designed specifically for residents with advanced dementia. Namaste Care was so unique that in one situation, the surveyors asked if they could recommend that other facilities visit to learn about the program.

From a business prospective, EPOCH found that referrals increased when discharge planners and geriatric case managers learned about Namaste Care. Keeping beds occupied drives the profit in long-term-care so making sure that a facility is viewed by healthcare professionals and prospective families as one that provides excellent dementia care is important. Namaste Care has been relatively simple to implement and the results have been impressive. EPOCH Senior Living has embraced Namaste Care and in doing so has helped to give a "voice" to their residents with advanced dementia.

While originally developed for residents with advanced dementia, as more facilities opened programs staff members realized that other residents could benefit from the soothing atmosphere of the room and the specialized activities. Residents with advanced COPD, Parkinson's disease and other terminal illnesses responded in a positive manner while in the Namaste Care room. Staff have reported that residents who pace continuously, somehow find their way into the Namaste Care room and actually will sit down! Sometimes even fall asleep! Out of desperation, staff members have taken residents who are agitated and all attempts at calming them fail, will try them in the Namaste Care room. One particular resident spent the majority of the day crying "help me". Staff members could not seem to find a way to comfort her and in desperation they

brought her to the Namaste Care room. She ceased crying out and spent the last days of her life smiling and napping in the arms of Namaste. Another resident who has end stage Parkinson's disease and is in a prone position in a lounge chair now has some reaction to a mobile hanging from the ceiling over her chair. Her husband believes that she has some awareness that she is with others and he is comforted by this.

Namaste Care also now includes "after death care". Most nursing facilities would rather not have a residents body taken through the common area of the facility and when a resident dies the resident is taken by mortuary staff to a back entrance where the hearse is waiting. Namaste Care however says "good bye" in a more public manner. Each resident's death is honored as their body is covered with a quilt or a flag if the resident was a veteran. The body is taken through the facility accompanied by staff and family. It is the Namaste way of saying "good bye" to a treasured friend.

Namaste Care is one example of how health care providers can hear the voices of residents with advanced dementia. The program simply responds to the basic human needs to be touched with compassion, to be present with others and to be loved. The lessons of life can perhaps be found in the care of the dying.

*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  
If you'll teach me to die  
I will teach you to live*

*Deanna Edwards (9)*

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