

# Help me, help me

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**Abstract:** Disruptive vocalization and resisting personal care is a problem for staff in most skilled nursing facilities. Often these behaviors result in the resident being treated with antipsychotics. The Namaste Care program which takes place in a calm environment and offers a loving touch approach to care, has been successful in eliminating these behaviors. The room or space where Namaste Care takes place is as free from disruption as possible and as the resident is welcomed into the room, the calming music and scent of lavender surrounds them. In this case report, the resident stopped crying out as soon as she entered the room. This resident also became comfortable with being touched when touch was offered in a slow, loving manner. Much to the delight of staff this had a “trickle down” effect as the resident stopped resisting care even when she was out of the Namaste Care room. The result was that this resident’s last year of life was filled with loving care until she took her last breath.

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“*Help me, help me*”, Agnes cried! She was in a wheelchair so I knelt down to be at eye level with her. Agnes did not like to be touched so I had to connect with her by my presence. “*How can I help you?*” I said, “*Help me, help me*” was her response. Agnes grabbed our hearts, those of the staff, of families visiting their loved ones, and mine, a social work consultant who (in my own mind) should have been able to “fix” this sad situation. Occasionally, Agnes would say “*My head hurts*”, but most of the time, whenever she was awake, “*help me, help me*”, was all she would say. Her physician had tried a variety of medications but none worked and all had side effects (1), so the best we could do was try to spend time by her sitting next to her. When we did this, she seemed comforted and cried out less often. In the busy life of staff in a skilled nursing facility, finding time to sit by her side was frustratingly difficult.

Agnes had moved into the facility many years ago sharing a room with her husband. They had no children and her husband had died several years before I met Agnes. Staff reported that they never saw anyone visit her; except for our staff she was alone. Her cries were so upsetting to other residents that she was rarely brought to an activity. Most days, Agnes was placed in front of the nurse’s station

so they could keep an eye on her and try to sit with her when she cried out for help.

Despite the heavy workload, all staff, tried to find time to pay attention to Agnes. She had a “crush” on two male aides and whenever Agnes saw them, her arms would open for a hug and they always stopped to comfort her with a gentle hug. This was the only time I ever saw her smile. I’m a hugger but I found out very quickly that a hug from me was definitely not welcomed and the cries of “help me” increased in volume when I tried to hug her. I felt as if I was a miserable failure in my role as a social work consultant not finding a way to increase the quality of her life.

Agnes also did not like to be touched so giving her a bath was a challenge. Sometimes it took several aides to bath her. In the morning when staff gathered around the nurse’s station they would wonder (sometimes aloud) “who gets her today?” And, everyone knew who “her” was.

I consulted with both social work and the activity department in this skilled nursing facility. The activity department had some interesting programs for residents without memory loss but on the secured neighborhood, they only had a few programs in the morning and one or two in the afternoon. When no activity professional was

engaging residents with moderate loss, they fell, “shopped”, taking items that did not belong to them, often resulting in an altercation, slept and then were awake so early in the morning they were given hypnotics. I also thought they looked sad, perhaps depressed, but because of their memory loss, counseling was not an appropriate treatment. I also realized that antipsychotics with the many side effects associated with this type of medication were not a good answer. So, we developed The Club, a program of continuous activities (2), so residents with moderate dementia had someone engaging them throughout their waking hours, even after dinner! It was very successful and led to a significant decrease in the use of antipsychotics and falls (3). I went on to consult with other skilled nursing facilities and speak at conferences and thought about retiring!

Then, I received a call from the administrator urging me to come back and develop a program for residents who were in the advanced stage of an irreversible dementia and could no longer participate in the Club. These residents were kept fed, well groomed and changed but as they were unable to actively participate in the word games, physical exercise programs and trivia discussions, they were often placed in front of the television where they fell asleep. To me, they were existing not living!

With the support of management and the creativity of a rehabilitation aide, we created Namaste Care, a group program of meaningful activities for residents with advanced dementia (4). A plain looking day room was transformed into a beautiful living room. We had little money but found “bargains” in the local Goodwill store and the generous donations of staff and families. Little did we know that this program, I called Namaste Care based on something I read that said the meaning of Namaste was “to honor the spirit within”, would not only be welcomed throughout the United States but would fly over the ocean. And become an international program. Namaste Care can be found in Australia, England, Scotland, St. Thomas, Canada, Iceland, Iran, and this year will be introduced in Singapore, Taiwan and the Czech Republic.

Namaste Care has two basic principles (5). The first one is creating a calm environment, where we make the room or space where Namaste Care will be offered as free from distractions as possible. The lights are lowered, a scent of lavender or some other familiar scent permeates the room and beautiful music fills the air. As residents are brought to the room they immediately feel this sense of calm. The second principle is a loving touch approach to everything the staff offers. From the moment, they are brought into

the room and are greeted in a person-centered way, a hug or handshake, to all “meaningful activities”, gentle washing and moisturizing of their face, arms, hands and legs and combing or brushing their hair. All touch is offered without gloves unless there is an infection control issue, and all touch is offered as an activity, where the “process” is more important than the task. One family member told me that when she enters the Namaste Care room, she feels as if a giant hug envelops her!

The program had been progressing beautifully and we were having some very positive outcomes. Residents were staying awake, they were smiling when offered these “meaningful activities”, many who were not speaking started to verbally respond to the Namaste Care staff, much to our surprise and delight. Staff and family members were very positive and this consultant (me) was delighted!

A few weeks after Namaste Care began, I stood watching the Namaste Carer offering hand massages and gently moving from one resident to another with beverages that the residents were greedily consuming! These were the same residents, who had only taken sips of liquid during breakfast. I must admit, I was feeling quite smug that the program was going so well, so quickly. Then the door opened and one of Agnes’s favorite male aides brought her into the room. I was shocked, as the aide knew that we could not have anyone crying out in the room that would have spoiled the essence of the program. As I stood there unable to figure out what to say, he spoke: *“We have tried everything to help Agnes stop crying out, could I at least try Namaste Care, we are desperate to do something for her. I promise to stay with her and if she starts saying, ‘help me’, I’ll take her out.”* He gently transferred Agnes from her wheelchair to a comfortable recliner, and then he tucked a soft blanket around her. This aide knew she loved coffee and he had a cup ready for her. Agnes looked surprised as she surveyed the room but she then surprised us by sipping her coffee...silently.

Agnes became the Namaste “miracle” as she spent the last months of her life comfortably seated in the room almost never crying out. As the weeks passed, Agnes began to allow staff to give her hand massages and fuss with her hair. She even began to smile! To everyone’s amazement, Agnes stopped resisting care, bath time was no longer a struggle. It appeared that as she started accepting of the gentle touching offered in Namaste Care, personal care became less frightening for her, sort of a “trickle down” effect of what she was experiencing during the day. This change in behavior has been noted in other care homes which established Namaste Care program (6).

I happened to be making a consultation visit the day Agnes died. She had been moved to a private room and appeared comfortable. Staff had placed favorite rosary beads in her hands and she was receiving oxygen. Staff tried to sit by her bed when they had time, but most of the time, Agnes was alone. At the end of the shift, one aide clocked out and came back as a volunteer to sit by her side until she died. The Namaste Care Program had helped to change the quality of life and death for Agnes. She had transitioned from “who gets her today”, to staff volunteering to sit by her bedside holding her hand, until she joined her husband in death. The cries of “help me” had been answered; we were finally able to help her.

### Acknowledgements

None.

### Footnote

*Conflicts of Interest:* The author has no conflicts of interest to declare.

*Informed Consent:* The patient has been deceased for over 10 years and had no family. Records are destroyed every

5 years so there is no information about this resident. And the informed consent could not be obtained from this patient.

### References

1. Sloane PD, Davidson S, Buckwalter K, et al. Management of the patient with disruptive vocalization. *Gerontologist* 1997;37:675-82.
2. Simard J. The lifestyle approach. In: Volicer L, Bloom-Charette L, editors. *Enhancing Quality of Life in Advanced Dementia*. Washington, Bristol, London: Taylor & Francis, 1999.
3. Volicer L, Simard J, Pupa JH, et al. Effects of continuous activity programming on behavioral symptoms of dementia. *J Am Med Dir Assoc* 2006;7:426-31.
4. Simard J. *The End-of-Life Namaste Program for People with Dementia*. 2nd edition. Baltimore, London, Sydney: Health Professions Press, 2013.
5. Manzar BA, Volicer L. Effects of Namaste Care: Pilot Study. *Am J Alzheim Dis* 2015;2:24-37.
6. Stacpoole M, Hockley J, Thompsell A, et al. The Namaste Care programme can reduce behavioural symptoms in care home residents with advanced dementia. *Int J Geriatr Psychiatry* 2015;30:702-9.

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