

NAMASTE CARE: A PALLIATIVE CARE PROGRAM FOR PEOPLE WITH ADVANCED DEMENTIA

Alzheimer's disease has been described as a giant tsunami sweeping the world. It's one of those "good news, bad news" comments. We are cleaning up the water in third world countries and have practically eradicated polio; people are living longer. Good news! However, at the same time, countries that never faced people living long enough to have a dementing illness are struggling with how to provide the best care for people with an irreversible dementing illness such as Alzheimer's disease. It is estimated that over 40 million people worldwide have Alzheimer's disease and while a cure is not a reality for those we care for now, helping them live with quality in their lives until they take their last breath is definitely possible.

The key is to educate families, the general public and healthcare workers about palliative care. Most people believe that palliative care is about hospice and hospice means death. Palliative care is about managing symptoms, it's about living throughout the disease process. And, living with quality in a person's life is about having something meaningful to do for each individual throughout all stages of a dementia. Meaningful activities range from helping people with early dementia continue to help set the table or rake the lawn, engaging them in trivia games, recalling memories from the past, and just having fun.

During the middle stage when behavioral symptoms might be present, like wandering and becoming resistive to care, we can live in their world. We can continue to help them feel good about themselves by having a "volunteer group", sorting playing cards and drawing pictures for a children's hospital. I have found that by providing continuous activities in nursing homes and residential care communities falls can be reduced as well as the need for antipsychotic medication.

As residents transition into the advanced stage of Alzheimer's disease, they are often unable to participate in a traditional activity program and although kept clean, fed and groomed, their quality of life suffers. I developed the Namaste Care program to provide meaningful activities to residents with advanced dementia living in nursing homes or residential homes. It's so simple and does not require extra staffing, dedicated space or expensive supplies. What it does require is dedicated staff who have the desire to provide this special program.

I titled the program *Namaste Care*. Namaste is a Hindu work meaning "to honor the spirit within" and every component of the program honors the person as a unique individual. It takes place seven days a week because Alzheimer's disease is a seven day a week disease. When residents have had their breakfast they are invited to the Namaste Care room, greeted warmly by a staff person who has been designated as a Namaste Carer and made comfortable. For most residents this means having a soft blanket tucked around them and perhaps small pillows to help maintain comfort with arms and legs that may have contractures. They are offered beverages throughout the morning, and may experience having their hair brushed lovingly and their faces washed and moisturized. Hand massages often produce expressions of love even from residents who are no longer verbal.

The entire morning and afternoon sessions of Namaste Care are about palliative care at its best, quality of life without medications, futile hospitalizations and medical interventions that pose more burden than have benefits. Indeed quality of life until the end-of-life for the resident that is appreciated by their families and the staff. Everybody surrounds the resident with love and in turn they are themselves surrounded with love.

St. Christopher's Hospice in London has undertaken a research project to study outcomes of implementing Namaste Care in six nursing homes in the UK. Preliminary results show staff and families very satisfied with the program. One family member told me that when she enters the Namaste Care room with the scent of lavender permeating the room, beautiful music filling the air, and smiling faces from staff and residents, she feels as if she is being enveloped in a giant hug.

As the world struggles coping with the growing number of people with Alzheimer's disease, the path we must follow is of making sure that palliative care is understood and offered. That we believe this quote from the founder of the modern hospice movement Dame Cicely Saunders-

"You matter because you are you. You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but also to live until you die."

LIVE until you die, that is what Namaste Care is all about.

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