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Avalon Memory Care Homes

Safe Passage

A Unique Model for the Palliative
Care of Alzheimer's Patients

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A Unique Model for the Palliative Care of Alzheimer's Patients

By Dr. Daniel L. Griffin

In 1858, Jacob Bigelow, a renowned physician, said, "A physician's duties are to diagnose, to initiate treatment, to offer relief of symptoms, and to provide safe passage." In 1990, The World Health Organization defined palliative care as "the active total care of patients whose disease is not responsive to curative treatment." They added, "Control of pain, of other symptoms, and of psychological, social, and spiritual problems, is paramount."

Although palliative care has traditionally been a common method of care for patients afflicted with cancer or AIDS, it is finding growing acceptance for the treatment of

patients who suffer from the devastating effects of Alzheimer's and other chronic diseases. Palliative care is specifically intended to provide for the relief of symptoms.

In 1995, after exhaustive planning, Avalon Residential Care Homes, Inc. began establishing residential homes for the cognitively impaired, based upon a model of palliative care which is being studied by long-term care experts from around the world. This model is credited with sparking an entirely new movement in Alzheimer's care.

Richard Seib, founder of Avalon, explains, "The principles which guided the development of our

treatment model at Avalon were born of our disappointing discoveries when we visited long-term care facilities. We saw a definite deficit in the care of Alzheimer's patients. The facilities were often abysmally understaffed, with staff-to-patient ratios as poor as 1:16. Even in facilities which generally provided good care to other residents, we found the standard approach to the care of Alzheimer's patients to be medieval. Patients displayed obvious outward signs of distress -- clinging, pleading, fearfulness. When we questioned the administration at these facilities, we heard almost universally that 'this is just the way Alzheimer's

All residents reside in master bedroom suites at Avalon Memory Care Homes.



patients are.’ “We thought we could do better, and we set out to develop a program of care based on common sense. We learned that our approach closely matches that of palliative care.”

Avalon’s model of palliative care is based upon the following precepts. Avalon provides care that:

- Affirms quality of life and integrates dementia with life activities.
- Neither hastens nor postpones death.
- Provides active relief from distressing symptoms naturally and effectively.
- Integrates the psychological and spiritual aspects of care.
- Offers a support system to help residents live as actively as possible.
- Allows the resident to live out his or her days without confrontation.
- Is “patient-friendly” and thereby helps the family to cope with the impact of the patient’s illness.

The goal of Avalon’s palliative care model is the achievement of the highest possible quality of life for patients and their families, for the longest period possible, rather than extending the patient’s life span in the absence of quality of life. In palliative care, the patient’s symptoms, rather than their disease, determine the approach to treatment. In cases where no cure is possible, aggressive medical treatment itself may cause unnecessary suffering. In this model, success is measured by relief of symptoms and suffering, not by termination of the disease or even by prolongation of life. “Our model of care is very effective in reducing and eliminating the symptoms commonly experienced by Alzheimer’s patients,” Seib notes. “Nearly 70 percent of our patients are incontinent upon arrival at Avalon. In 70 percent of those cases, the incontinence is resolved within a week.”



Families and staff gather after lunch to reminisce at one of our Dallas locations.

Practicing palliative care requires a shift in thinking from the traditional medical model, which recognizes the primary aim of healthcare as curative. For example, Avalon has found that, in the case of Alzheimer’s care, reducing medications to the lowest reasonable level can frequently extend both the quality and quantity of life of their patients. “By assuring appropriate and minimal levels of medication, we give our residents the resources they need to be happy, comfortable and secure,” Seib adds. “Our non-traditional approach to care allows them to be a person.”

Because palliative Alzheimer’s care has evolved outside the hospital setting, most students and physicians-in-training in American medical schools are not trained in the care of patients with Alzheimer’s. The benefits of palliative care for these patients are becoming more widely acknowledged, and as a result, a number of components of the

palliative care program implemented at Avalon’s homes are now being considered for inclusion in the curricula at universities.

Experience in palliative care has resulted in an increased understanding of the crucial value of symptom management, especially with respect to pain, but also dyspnea, nausea and vomiting, constipation, confusion, anxiety and depression, anorexia, weakness, hallucinations, disorientation and other symptoms. Pharmaceutical management and complementary therapy have been demonstrated to be of tremendous value.

In addition, there is a growing acceptance of the importance of psychosocial issues and the recognition that there is an irreplaceable magic in life which springs from our relationships with loved ones. In her book, *Facing Death and Finding Hope*, Christine Longaker says, “To be told that you are dying is not the worst thing that can happen to you. The worst thing

is to feel abandoned.”

Individuals who suffer from Alzheimer’s disease need to feel a deep and meaningful correctness with their closest loved ones. This often includes personal caregivers who provide palliative care and have an understanding of dementia. Seib explains, “Alzheimer’s patients live in a world of absolute truth. Rather than disrupt their reality by forcing our ‘correct’ views of the world upon them, we allow them to live comfortably in their world. Imagine how distressing it would be to find your perceptions of reality constantly challenged by those around you. At Avalon, we recognize that it is terribly upsetting, damaging and ultimately counterproductive to constantly confront and press a patient to distrust his or her perceptions of the world around them.” At Avalon, caregivers and

family frequently bond in a loving union centered around the patient. In a talk in Houston three decades ago, Kubler-Ross, the author of *On Death and Dying*, said, “All that really matters at the end is the love you have given and received.”

Good palliative care provides a framework in which patients, families, and caregivers can express their thoughts, fears, and concerns about the illness in an open and accepting atmosphere. The way in which the patient is cared for can have a profound effect on the surrounding family.

Workers in the field of palliative care must be prepared at all times to address spiritual concerns. This does not mean imposing one’s own beliefs, but rather listening to the patient and family with an open mind and open heart, with respect and unconditional love. Simply directing families

toward uninhibited expressions of love can have a profound spiritual effect. The age-old practice of the gentle Tibetan Buddhist monks is to give all of their love without reservation -- to shower the person suffering from dementia with love, trusting that it is getting through even if there is no visible response.

At Avalon Residential Care Homes, patients are afforded the comfort of palliative care, and relief from the pain and suffering that is commonly associated with dementia. In *Man’s Search for Meaning*, author V. Frankl notes, “In the struggle to find meaning, it is the one who is ill who helps the one who is well.” Avalon’s unique model of care creates a climate in which love and spiritual growth can occur for those administering treatment as well as for the patients in their charge.

Newly constructed National Award Winning Dementia Care Homes

