



Hospice of the Twin Cities

Hospice Insights

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*“You are richer today
if you have laughed,
given, comforted,
healed, or forgiven.”*
- Jack Bongioni, M.D.

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Alzheimer's Dementia and Hospice

Alzheimer's dementia is steadily increasing in the United States. Currently, about one percent of the nation's hospice programs serve people with dementia. Unless there is a cure, or preventative treatments, the number of people diagnosed with Alzheimer's will triple by the middle of this century (4 million > 14 million).

Facts about Alzheimer's Dementia:

- ◆ Alzheimer's is a progressive and degenerative disease with an unknown cause.
- ◆ Currently, 10% of the population over age 65 has Alzheimer's and 50% of the population over age 85 has Alzheimer's.
- ◆ Alzheimer's is on the increase for middle aged people.
- ◆ Individuals diagnosed with Alzheimer's have a 3-20 year life span from the onset of the disease (the average survival rate is 8 years).
- ◆ Alzheimer's can only be accurately diagnosed by a brain autopsy.
- ◆ Alzheimer's is a disease with a gradual onset which progresses in the following pattern:
 - Short term memory loss,
 - Struggle to find words, finish thoughts, follow directions,
 - Forget names and faces of family and friends, and
 - Become fully dependent on a caregiver.

The primary focus of care for individuals who have a diagnosis of

Alzheimer's is to provide them with a safe and supportive environment. [Picard, D. (Fall 1997) A good mix waiting to happen – Alzheimer's is on the increase and hospice can play a role.

Can Hospice Benefit an Individual with Alzheimer's and Other Dementias?

Often it is asked, "How can hospice benefit or impact an individual with Alzheimer's/dementia?" It is difficult to understand how it can until we look at one of the main goals of hospice and that is ***“enhancing the quality of life”***.

How hospice enhances the quality of life is not only a subjective observation, but can be objective and quantitative in many aspects. Clearly engaging hospice services to relieve physical pain and symptoms can have a measurable outcome; however, when hospice attempts to relieve the emotional, social, and spiritual suffering the evaluation becomes much more subjective. Everyone has a different opinion on the outcome or success of the hospice team.

Many positive outcomes have been noticed when hospice care has been provided to individuals who are "unaware of their surroundings". In an effort to comfort those with Alzheimer's and other types of dementia, the following are

Basic End-Stage Indicators:

- ◆ Overall physical decline
- ◆ Life limiting condition
- ◆ Clinical progression of the disease as evidenced by
 - Multiple ER visits
 - Inpatient hospitalizations
 - Serial physician assessment
 - Laboratory studies
 - Radiologic or other studies
- ◆ Impaired nutritional status
 - Decrease in appetite; increase in wt loss
 - Serum albumin <2.5mg/dl (not to be used in isolation)
- ◆ Multiple co-morbidities
- ◆ Decline in functional status (ADLs)

Specific Guidelines for determining Prognosis

End-Stage Dementia

- ◆ Patients with dementia must show all of the following characteristics
 1. Stage seven or beyond according to the Functional Assessment Staging Scale (FAST).
 2. Unable to ambulate without assistance.
 3. Unable to dress without assistance.
 4. Unable to bathe without assistance.
 5. Urinary and fecal incontinence, intermittent or consistent.
 6. No meaningful verbal communication, stereotypical phrases only, or ability to speak is limited to six or fewer intelligible words.
 7. Patients must have one of the following within the past 12 months.
 - Aspiration pneumonia
 - Pyelonephritis or other upper urinary tract infection
 - Septicemia
 - Decubitus ulcers, multiple, stages 3-4
 - Fever, recurrent after antibiotics
 - Inability to maintain sufficient fluid and caloric intake with 10% weight loss during the previous six months or serum albumin <2.5 gm/dl.

Alzheimer's Dementia (Cont.)

benefits we see at hospice:

- ◆ Recognizing each individual as someone with intensive physical and emotional needs **maintains the dignity** of that individual because care then center around the unique and fluctuating needs of each patient.
- ◆ Facilitating non-verbal communication during cares, providing calming stimuli, and exhibiting sensitivity to individuality are interventions that **promote the emotional security** of the individuals with Alzheimer's/Dementia.
- ◆ Sensory deprivation and social isolation are known factors which cause undesirable behaviors in individuals with Alzheimer's/ Dementia, therefore, the presence of another human being, especially at the end of life, would **provide comfort** and have a tendency to **minimize undesirable behaviors**. There are some techniques that are very useful in addressing these aspects of care: Use a soft tone of voice; choose calming words; play relaxing music, including classical, new age, nature sounds, etc.; touch is very therapeutic, and the gift of presence is always welcomed.

- ◆ **Hospice focuses on quality of life, not quantity of life.**

This is true for all individuals with a limited life expectancy. Experience indicates that a short visit (15-20 minutes) with an individual with Alzheimer's/dementia is extremely beneficial. We have been told by long-term care staff that a short visit by the hospice volunteer has calmed an otherwise agitated hospice patient for the whole day ~ one cannot over-rate the **"gift of presence"**.

- ◆ Families of individuals with Alzheimer's/Dementia benefit knowing their loved ones have extra attention and care provided at the end of their lives. This knowledge **eases the family's burden** of being the sole care-givers outside of the long-term care staff.

It is easy to answer the question "Can hospice truly make a difference with the Alzheimer's/dementia patient?" **ABSOLUTELY!!** It is extremely important for all caregivers to keep focused on the needs of the patient and, in doing so, the answer to that question will always be **ABSOLUTELY!**

Reference:

Berkley, D., Brady, R., Brown, J., et al, 1988. Clinical management of Alzheimer's disease. Aspen Publishers, Inc., Rockville, Maryland.



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Mission Statement

Hospice of the Twin Cities' mission is to enhance the quality of the lives of our patients and their families by providing respectful care based on maintaining dignity, alleviating physical, psychosocial, and spiritual suffering, advocating for fundamental rights, and affirming the sacred value of life.