

Why look at palliative care through a dementia lens?

Palliative care

The purpose of palliative care is the prevention and alleviation of pain and suffering. The earlier that palliative care is involved, the better, when someone has been diagnosed with an acute, chronic and/or terminal illness; while other specialists are treating the disease(s), palliative care focuses on symptom management, helping to ease stress for the person and for their family, including symptoms such as depression, pain, anxiety, or difficulty sleeping or breathing. Some research studies suggest that this additional level of support and attention to comfort and quality of life may even prolong life. Further, a focus on personal priorities with regard to treatment and comfort can help clarify preferences for medical care directives as the disease(s) progress. This person-centered focus has been shown to reduce the need for crisis hospitalizations.

The palliative care disconnect for people with Alzheimer's and other dementias

Alzheimer's is a progressive, terminal disease; the average time between diagnosis and death is 8 to 10 years, but it is extremely variable and can last up to 20 years or more; typically, about 40% of this time is spent in the advanced stages. Palliative care has the potential to offer more over a longer time period for people with dementia; however, unless there are specific modifications in how palliation is offered to people with dementia, there is a strong possibility that it will be ineffective. Far too often, palliation isn't even considered as an option for people with dementia.

Palliative care does not mean giving up; it means taking active steps to discover what comforts someone and even gives them pleasure, and taking active steps to prevent or avoid unnecessary pain and suffering before they take hold. As an individual's dementia advances, his/her actions, rather than words are most likely to communicate distress. Unfortunately, all too often these behavioral expressions are not understood as distress; rather they are often assumed to be the inevitable consequences of the dementia itself. Palliation cannot occur if the reason or triggers for distress are not known or understood. Anti-psychotic and anti-anxiety medications do not take away pain, nor do they comfort if someone living with dementia is hungry, cold, too warm, tired, or frightened by noises or activity in their environment.

Dementia-capable palliative care applies dementia-specific practices and tools to evaluate and to respond appropriately to people with advanced dementia. In particular, this means (1) use of a behavior-based pain assessment tool; (2) use of round-the-clock rather than PRN orders for pain medications; (3) offering food in small, manageable amounts, especially finger food, throughout the day and evening; (4) essential flexibility for rising, eating, bedtime and other routines; (5) attention to the person with dementia's needs for a delicate balance of stimulation and rest in the environment, and for the individual throughout the day.

Advance Directives

Dementia-capable care practices aren't the whole story. Significant decisions must be made regarding aggressive medical treatments, traditionally used with the goal of curing, which are more often than not inappropriate for someone with advanced dementia. Specifically for the persons with dementia, these include (1) artificial nutrition through gastric tube feeding; (2) antibiotic therapy; (3) cardiopulmonary resuscitation (CPR); (4) hospitalization for infection. These are highly individual decisions that must be made based on the person's values and best interests. People with dementia and their families need information and understanding about how to weigh the risks and benefits. Palliative care decision points are reached when the person with dementia is beyond understanding, and it is essential that family be involved, and provided with appropriate education and support.