



# HOSPICE INSIGHTS

**Volume 87: Quality of Life for Individuals With Dementia January, 2005**

“Quality of Life” (QOL) is a very important goal for physicians in caring for their patients. When a patient is suffering from any form of dementia this becomes very difficult for the physician to achieve, mainly because of the diminishing cognitive capabilities of the dementia patient. QOL is also difficult to measure because of their limited ability to communicate, virtually making it almost impossible to seek information based on the “patient’s report”. So, how can we determine if a dementia client has QOL?

There are a few QOL models for dementia patients. The following are two of them:

- M.P.Lawton’s (Alzheimer Dis. Assoc. Disorders, 1994) definition of QOL encompasses four domains:
  - Psychological well being
  - Behavioral competence
  - The objective environment
  - Perceived QOL
- L. Volicer (Clin. in Geriatric Medicine, 2001) developed another model for patients with severe dementia:
  - Provision of meaningful activities
  - Treatment of medical conditions
  - Management of behavioral symptoms

Even with these models there are no set guidelines for ensuring QOL for those with dementia. However, Sandy Burgener (1998) has developed QOL guidelines and interventions that are very helpful in caring for those individuals with dementia. They are as follows:

Patient Experience	Intervention
Pain and Comfort States	Observe nonverbal pain expressions. Educate caregivers regarding patient’s expression of pain. Integrate pain assessment into caregiving routine.
Individual touch experiences	Observe verbal and nonverbal responses to touch. Individualize use of touch based on patient response.
Structural care routine	Follow familiar pattern of care. Build care pattern around “routinized” behaviors.
Low-stimulus environment	Reduce extraneous noise. Reduce crowding or unfamiliar persons or objects. Avoid misleading or distracting stimuli.
Health	Provide palliative care interventions.
Time use and social behavior	Assist family/friends in understanding the patient’s need for contact. Encourage visiting by close family members/friends.

From a hospice perspective it is important to note the reference made to addressing the “pain and comfort states” of the dementia patient. It is also important to note that two of the dementia experts cited, Volicer and Burgener, address the need to take care of the dementia patient’s medical needs and Burgener specifically states the need to provide “palliative care interventions”, which emphasize maintaining the QOL of the individual while avoiding unnecessary aggressive or restorative treatments.

Hopefully, these guidelines will enable all of us to take better care of those with dementia. The February, 2005 Insights will look at the different approaches towards end-of-life care for dementia patients.

**References:**

- Burgener SC: *Quality of Life in Late-Stage Dementia in Hospice Care for Patients with Advanced Progressive Dementia*. Edited by: Volicer L, Hurley A. New York: Springer, 1998, pp 88-113.  
 Lawton MP: Quality of life in Alzheimer disease. *Alzheimer Dis Assoc Disorders*. 1994;8 Suppl 3:138-50.  
 Volicer, L: Management of severe Alzheimer’s disease and end-of-life issues. *Clin in Geriatric Medicine*. 2001; 17(2):377-391.

*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.*