



End-of-Life Issues

Dementia is both a disease and a life journey for patient and family. Like all journeys, there is a beginning and an end. Most patients with dementia follow a progressive course that intellectually disables the patient. Dementia is caused by the death or permanent dysfunction of nerve cells. After five or ten years of dementia, the patient loses the ability to walk, talk, eat and respond to the external environment. Patients eventually become bed-bound and require tube feeding as well as constant nursing care. Meticulous nursing care limits complications such as decubitus (bed sores) or contractures (drawn up arms and legs); however, most patients develop these problems late in the disease. Families must make important medical and quality-of-life decisions for patients.

End-stage dementia patients usually lack the ability to make informed decisions, recognize family and decide treatment options. Medical staff will use all means possible to prolong the life of dementia patients without directions from the family. When families disagree about care, doctors will do everything possible to keep elders alive. Doctors worry about the angry family member who "wants everything done for Momma." Patients will be placed on ventilators (breathing machines), receive pace makers, have tubes inserted into major vessels and undergo surgical procedures for insertion of feeding tubes (PEGS) through the abdominal wall. These invasive procedures are expensive, painful and rarely add to the quality-of-life. Severely demented patients do very poorly on ventilators (breathing machines) because they lack the ability to cooperate with Intensive Care Unit staff. Most dementia patients continue to recognize painful stimuli late into the illness. These individuals may not understand the pain but still perceive the hurt. It is unclear if patients perceive hunger or discomfort due to not drinking or eating in the end.

Families should discuss life planning and treatment choices with patients while they remain cognitively intact. Most elderly patients have considered these options and have strong opinions. Most elders will not conclude that the family is "trying to get rid of them" but the family is usually respectful of the elder's opinions. This

allows families to abide by patient wishes. Advance directives such as living wills are very helpful for both patient and family.

Families should discuss prognosis and treatment options among themselves prior to confronting a medical emergency. The family should develop a consensus approach to avoid conflicting direction during a medical emergency. Physicians will use all means possible to prolong life if one family member insists on extraordinary measures. The pastor for the family or facility can assist with decision-making when appropriate. The family should seek advice from pastors who understand dementia and the terminal nature of the disease. Many pastors do not understand that the dementia patient's brain is dying.

Most dementia patients die from pneumonia or blood-borne infection originating from the urinary tract system. Families can ask for a range of medical care that does not include extraordinary measures (i.e., breathing machines, pumps etc). IV antibiotics, short-term IV fluids and appropriate heart medication may be indicated for some end stage patients.

Family must discuss the insertion of feeding tube and other measures to sustain the nutrition. The physician should give families a range of options for patient management. Families may also use hospice to promote quality-of-life and dignity during the dying process.

Terminal Alzheimer patients should have appropriate pain-control. Medical problems, degenerative joint disease and contractures from immobility can produce pain in the dementia patient. Physicians should use appropriate doses of narcotics to minimize pain and suffering for the terminal dementia patient. This management is well-suited for hospice care.

Following the patient's death, family may wish to attend support groups for grieving family or seek individual counseling. The treatment team should provide referrals and encourage family to consider counseling. Family may also continue to attend dementia support groups and share their wisdom with others.

Families should know that too much treatment is as bad as too little treatment. Dignity, respect, and quality of life are the treatment goals for end stage Alzheimer patients. Healing and resumption of life are the caregiver's goals at the end of this journey.