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Current research indicates that some 67% of dementia-related deaths occur in long-term care (LTC) facilities.¹ The Alzheimer's Association, a voluntary health organization that provides Alzheimer's care, support, and research in the United States, recently released the third phase of its evidence-based Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes, which covers end-of-life care practices and issues.

An interdisciplinary team of dementia experts (including physicians, researchers, social workers, and nurses) agreed that communication and advance planning are central to quality care because they "permit residents to receive the care that they would want if they could speak for themselves, and enable families to make the best possible decisions on behalf of their loved ones."² The timing of communication about end-of-life and care planning meetings, establishing a proxy decision maker, and educating the resident and family about care and treatments are discussed in detail, and special attention is given to matters such

as weighing risks and benefits of pharmacotherapy for residents at the end of life. The guide's section on physical symptoms urges training of direct care workers, who are often the first to notice changes in residents' behaviour or symptoms, to recognize and report symptoms that may suggest pain or distress. The recommendations regarding behavioural symptoms remind the care team that behavioural interventions should only be pursued if the behavioural symptom is distressing to the resident involved or poses a risk to the resident or others, and after the source of the behaviour has been determined not to be untreated pain, dehydration, or some other physical symptom.

The recommendations foreground support for the family of patients with dementia. Long-term care facilities are advised to make staff available to educate, counsel, and comfort family members about the signs of approaching death, what will happen when death occurs, and the multiple-stage grieving process that takes place when a loved one dies with dementia.

The recommendations conclude that improving the conditions for individuals dying with dementia in long-term care will become more and more important as the population ages; implementation of these practices will contribute to the experience of a comfortable, dignified death for the individual and a caring, supportive environment for their family. 

References

1. Mitchell SL, Teno JM, Miller SC, et al. A national study of the location of death for older persons with dementia. *J Am Geriatr Soc* 2005;53:299-305.
2. Tilly J, Fok A. Quality end of life care for individuals with dementia in assisted living and nursing homes and public policy barriers to delivering this care. Alzheimer's Association 2007.