

ADVANCE DIRECTIVE NEWS

The Nursing Home Dilemma

By Ellen G. Makofsky

It is no secret, people die in nursing homes. The thesis of this Advance Directive News column is that more people should die in nursing homes. Increased nursing home deaths, of course, should not be the result of poor care but rather as a natural end to a life.



Statistics show that currently more than 20 percent of the aging population die as residents of nursing homes. This is not an unexpected statistic. Residents of nursing homes are often old and frail.¹ The statistic which is disturbing is the one which demonstrates that 30 percent of all patients who die in a hospital were transferred to that hospital from a nursing home just a few days earlier.² It is this 30 percent of residents who have been discharged from the nursing home into the hospital that should rouse concern.

Nursing homes are understandably often hesitant to embrace death. One of the main tenets of modern-day nursing home quality standards is a denial of the idea that the facility is a waiting room for those about to die and that decline is inevitable for nursing home residents. The Department of Health along with nursing home administrators and their staffs are committed to improving the physical, mental and social health of nursing home residents and/or maintaining the status quo of the resident. The idea of maintenance and improvement over mere caretaking has directed nursing homes toward a less fatalistic care model. Of course, this change in itself is good. No one wants sub-standard care. The problem is that when a nursing home is treatment-based, and provides lots of physical therapy, occupational therapy and other health-promoting expectations, an unintentional byproduct may be created—the culture of death denial within the nursing home.³

Feeding into the death denial culture are Department of Health regulations that impose standards on nursing homes which assume that physical, mental and/or emotional decline may be signals of deficiencies in nursing home care unless demonstrated otherwise.⁴ Nursing home administrators are very sensitive to regulatory risk. This sensitivity may in some cases dissuade the nursing home from encouraging the peaceful passing of the nursing home resident within the facility. Department of Health regulations skew nursing home care models away from the care of the

dying. Thus, it is not uncommon for a dying resident to be transferred to the local hospital so the inevitable death will not occur in the nursing home and require that the quality of care of the resident be defended.⁵

Those who have resided in the nursing home for a period of time can find comfort in familiar surroundings. Each nursing home resident is unique with a different health history and individual preferences in regard to end of life. Hospital care often provides a more aggressive intervention than will be found in a nursing home. If the resident wants to forego hospital treatment, then the resident has the right to state such preference and have his or her wishes honored. Where there is a lack of capacity, and a health care proxy in place, the health care agent has the right to notify the nursing home not to call 911 or otherwise direct the resident to the local hospital. Our clients and/or those who serve as health care agents are often unaware that they have the right to refuse care. We need to educate them.

Endnotes

1. As is so aptly stated by Joanne Lynn, "Not long ago, people generally 'got sick and died'—all in one sentence and all in a few days or weeks. The end of life had religious, cultural, and contractual significance, while paid health care services played only a small part. Now most Americans will grow old and accumulate diseases for a long time before dying. Our health care system... supplement[s] the body's shortcomings," [and makes] "it possible to live for years 'in the valley of the shadow of death.'" Joanne Lynn, "Living Long in Fragile Health: The New Demographics Shape End of Life Care," *Improving End of Life Care: Why Has It Been So Difficult? Hastings Center Report Special Report 35*, no. 6 (2005): S14.
2. Sandra H. Johnson, "Making Room for Dying: End of Life Care in Nursing Homes," *Improving End of Life Care: Why Has It Been So Difficult? Hastings Center Report Special Report 35*, no. 6 (2005): W37-S41.
3. Johnson, *supra* note 2 at S37.
4. N.Y. Public Health Law § 2803.
5. Johnson, *supra* note 2 at S37.

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