



# The First State-by-State Report Card on End-of-Life Care: How Did *Your* State Do?

In November 2002, the Last Acts coalition issued a report that graded all 50 states and the District of Columbia on eight key elements of end-of-life care. Grades of A, B, C, D, and E (which used to be called F when I was in school) were given to each state's advance directive and pain management policies, locations of where people die, rates of hospice use, availability of hospital end-of-life care services, utilization of intensive care unit (ICU) care at the end of life, pain reported by nursing home residents, and number of physicians and nurses certified in palliative care (Last Acts, 2002).

How well did your state do? To find out, go to the Robert Wood Johnson Foundation (RWJF) Web site at [ww2.rwjf.org/news/special/means.jhtml](http://ww2.rwjf.org/news/special/means.jhtml) and click the box "View our interactive state report card." RWJF launched Last Acts in 1996 and funded the coalition's "Means to a Better End" report on end-of-life care. The coalition is comprised of more than a thousand national and local partner organizations, including nursing organizations such as the Oncology Nursing Society and the American Nurses Association (Volkers, 2002). Detailed information about the state-by-state report card, grading method used, and implications for practice can be found at the Last Acts Web site ([www.lastacts.org](http://www.lastacts.org)).

No state did well across the board in all elements of end-of-life care; in fact, most states earned C's, D's, and E's on the majority of the criteria. Only seven states received an A for their advance directive policies. Many states have laws that contain confusing language or create bureaucratic hurdles for people wanting to express their end-of-life care preferences and designate surrogate decision makers. Many states also received low grades for hav-

ing laws governing controlled substances that create overwhelming barriers to effective pain management (Last Acts, 2002).



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According to a 1999 Harvard public opinion poll cited in the "Means to a Better End" report, 70% of Americans would prefer to die at home, but Last Acts found that only about 25% actually do. Where people die greatly depends on the community in which they live and the palliative care resources and services that are available locally. Although hospice care is recognized as an important component of end-of-life care, it is not widely used in most states. And patients who *do* receive hospice care commonly receive it for *less than a week*. Hospital end-of-life care services are expanding, and dedicated palliative care programs are increasing; however, these programs exist in insufficient numbers. In the last six months of life, the number of patients who spent a week or more in an ICU ranged from 3.4% in Oregon to 17.3% in New Jersey. Patients at the end-stage of disease who received care in ICUs typically received standard ICU care rather than palliative care (Last Acts, 2002).

Appropriate utilization of intensive care treatment for patients with cancer recently has received scrutiny; in a study of 100 patients in ICUs, only half were able to respond to a symptom assessment. Of those responding,

33%–75% reported that they experienced moderate to severe pain, anxiety, depression, dyspnea, sleep disturbance, and unsatisfied hunger or thirst (Nelson et al., 2001).

About half of the 1.6 million Americans residing in nursing homes report persistent pain that is under-recognized and under-treated. The Last Acts coalition calculated this incidence by determining the percentage of nursing home residents who were in pain when initially asked and who were still in pain when asked again 60–180 days later. States where fewer than 25% of nursing home residents have persistent pain would have received a grade of A. None did (Last Acts, 2002). Nursing home utilization is expected to increase in the next 20 years as the number of people 65 years of age and older increases by more than 50% (U.S. Census Bureau, 2002). These statistics have frightening implications for how and where health care will be delivered to older adults, especially at the end of life.

## Bringing Up the Grades

The Last Acts (2002) coalition recommended that federal health policy be reformed to better meet the needs of the dying. Seamless patient-centered palliative care is the goal. State policymakers need to revise the laws governing the prescribing of analgesics to ensure that healthcare providers with prescriptive authority are not afraid to prescribe analgesics when warranted. Healthcare leaders, as well as physicians and nurses, need to advocate for palliative care training for all

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