

ISSUES IN

End-of-Life Care

in Rhode Island

A Guide for Policy Makers



Rhode Island
Partnership to Improve
End-of-Life Care

End-of-Life Care

What are the Facts About End-of-Life in Rhode Island?

- Per capita, Rhode Island has the nation's second-highest percentage of elderly residents.
- About 10,000 Rhode Islanders die annually, with the leading site of care at the end-of-life taking place in a nursing home.
- Rhode Island leads the nation in the proportion of individuals who die in a nursing home. The Rhode Island average is greater than one in three while the U.S. average is one in four (24.1% U.S. vs. 33.3% RI).
- The majority of Rhode Islanders die of chronic illnesses such as heart disease (33%), cancer (25%), cerebrovascular disease (7%) and chronic obstructive pulmonary disease (4%). Nearly 2/3 of those deaths are in persons 75 and older.
- The make up of Rhode Island's population resembles what the entire nation's population will be in the year 2020 in terms of where people die. After adjustment for age and gender, R.I. was sixth in the nation for persons dying in nursing homes (See Figure 1, maps of the United States showing that since 1989 R.I. has led the nation in the percentage of people who die in nursing homes). Since nursing homes are caring for more dying patients, we must insure that they have the tools to provide coordinated, compassionate care.

We must all learn that dealing with those who are dying is not about dealing with death, but rather quality of life and living. We must explore how to help those facing their final days to live the remainder of their lives well.

*Senator Jack Reed
Rhode Island*

What is the Rhode Island Community-State Partnership to Improve Care at End-of-Life?

The R.I. Partnership to Improve Care at the End-of-Life is a collaborative effort among Brown University, the University of Rhode Island, Aging 2000, Rhode Island Quality Partners, Inc., key members of the Rhode Island State government, health care facilities and health care associations around the State. The partners are working together to educate consumers, health care providers and policy makers in order to improve the quality of care for those approaching the end of their lives in Rhode Island nursing homes. The Partnership is an initiative supported by a grant from the Robert Wood Johnson Foundation.

Why is the Partnership Necessary?

In the past century, there have been profound changes in how Americans die. At the turn of the century, people died quickly of infectious disease. Now, people die of progressive chronic illnesses, which are usually characterized by the slow loss of functional abilities.

Moreover, the U.S. health care system is framed not around chronic illness, but around acute illness. As a result, dying persons have largely been ignored by a health care system which focuses only on cures, and not on the appropriate alleviation of pain and other symptoms. This vulnerable population must also face the challenge of substantial health care cutbacks from the State and Federal governments.

When medical treatment is no longer effective or desired, we must insist that our loved ones end their lives free of fear, relieved of suffering, and treated with the dignity and comfort that they desire.



What are some of the key findings of the Brown University study?

(For further information on the Brown University study, please see our website: www.chcr.brown.edu/commstate/homepagewithframes.htm)

It is essential that public policy makers explore new ways to provide quality care for those of our citizens approaching the end of their lives.

Lt. Governor Charles J. Fogarty

“Twenty percent of the federal budget is spent on health care. Certainly, the federal government can do a better job of supporting a level of care that alleviates the suffering and fear associated with chronic illness and death.”

Senator Lincoln Chafee

Rhode Island

I. Need for Improved Pain Management

Finding: One-half of all families interviewed reported that their loved ones experienced pain at end-of-life.

- Family members reported that pain was present in almost half of the dying persons who were conscious in their last week of life.
- Two-thirds rated the pain as severe (i.e. moderately or extremely severe) more than one half of the time.
- Almost half of the respondents stated that pain treatment given to their loved ones was not explained to them in a way that they understood.

II. Need for Improved Advance Care Planning and Communication

Finding: Families reported an urgent need to improve the process of communication and implementing advanced directives.

- While three-fourths of the persons dying in nursing homes had an advance directive (such as a living will or power of attorney) outlining their preferred course of treatment, nearly half of those persons said that the advanced directive did not help in making treatment decisions.
- Because those who are dying are often transferred to a number of different health care settings, family members reported that continuity of communication was severely lacking in their loved one's health care.

III. Need for Improved Pastoral Counseling

Finding: Health care providers rarely refer dying persons to spiritual leaders

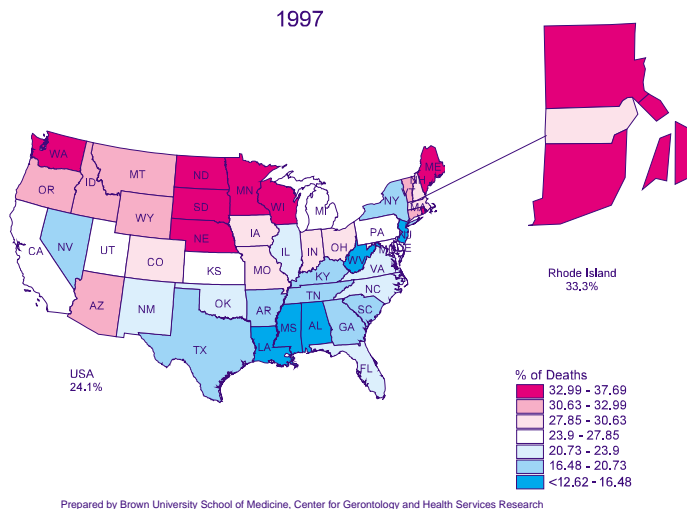
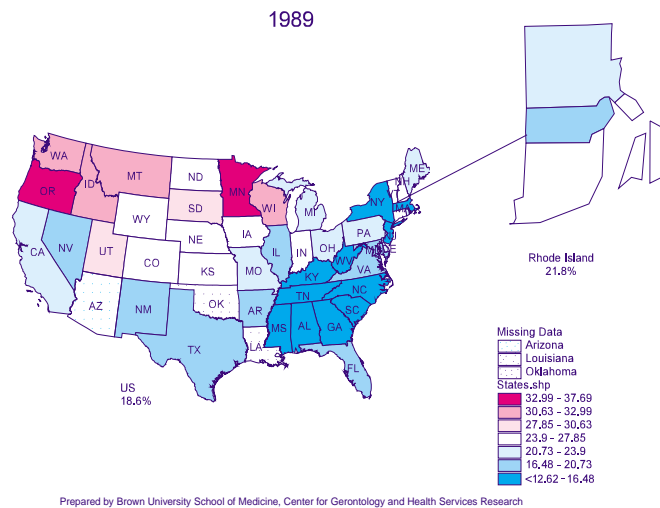
- While seventy-nine percent of families stated that a nurse really listened to their hopes, fears and beliefs as much as they wanted:
- Only forty-four percent said someone spoke to them about their religious concerns.
- Only fifteen percent were referred to a religious or spiritual leader by the health care provider.

Conclusion

The purpose of this guide is to provide you with a resource to help make informed public policy decisions about the health care of Rhode Islanders dying in nursing homes. The time is ripe for change. Policy makers have the power to make a real impact on the direction and magnitude of that change.

Proportion of Deaths Occurring in Nursing Homes

1989 vs 1997



Challenges for Lawmakers

Policy opportunities to improve coordination of care and pain alleviation for this frail and vulnerable population include:

- Developing specific indicators to measure the quality of care of dying persons in all health care settings, especially nursing homes. The results should be publicly reported.
- Making pain management a focus of the state's survey of nursing facilities.
- Ensuring that transitions between health care settings are seamless.
- Requiring that the state appoint a task force on end-of-life care.
- Requiring that state-supported schools of nursing and social work include palliative care content in their curricula.
- Requiring physicians and nurses to provide evidence of Continuing Medical Education credits in pain management, at the time they renew their licenses.
- Addressing the issue of access to hospice for the uninsured and education for health care providers on referral to hospice and palliative medicine.