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# Issues

Information and ideas for those  
serving seniors.

*on Aging*

## End-of-Life Care

Care at the end of life is a major concern for seniors and people with terminal illness, their families, and those who assist them in professional roles. Approximately 2.5 million people die each year in America, and 80% of them are Medicare beneficiaries. (Last Acts, 2002a). Medicare beneficiaries include both seniors and people who have received Social Security Disability Income for more than 24 months.

Last Acts, a coalition of more than 1,075 national and local organizations dedicated to improving end-of-life care, conducted surveys in cooperation with the Robert Wood Johnson Foundation to measure Americans' perceptions and wishes about end-of-life care. Findings from its 2002 report indicate there is significant discrepancy between the actual provision of terminal care in this country and the end-of-life preferences of many Americans.

### NATIONAL SURVEY RESULTS

According to the Robert Wood Johnson Foundation (2002b), these data summarize some major concerns in end-of-life care.

- Nationally, only 25% of deaths occur at home, although more than 70% of Americans say that this is where they would prefer to die.
- About half of all deaths occur in hospitals, but only 14% of hospitals offer palliative care, 23% offer hospice care, and 42% offer pain management services.
- Experts agree that patients need at least 60 days of hospice care to maximize its benefits, but the report found that hospice stays range from 14 to 43 days per state.
- At least one in four nursing-home residents in the U.S. experiences pain for at least

two months without appropriate pain management.

- A study of cancer patients in intensive care units found that 55% to 75% had moderate to severe pain, discomfort, anxiety, sleep disturbance or unsatisfied hunger or thirst.
- Only 24 states have pain management policies that explicitly address the needs of the terminally ill, and only 18 of these policies express concern about the undertreatment of pain in this group.

This recently completed national Robert Wood Johnson study found that many Americans have concerns about the quality of care provided to dying patients and their families. In many categories surveyed, nearly half of participants stated that care was poor or fair, while very small percentages of respondents indicated their care was excellent. This leaves room for considerable improvement in end-of-life care.

<b>How Americans Assess the Quality of End-of-Life Care</b> (Robert Wood Johnson, 2002a)	<b>Excellent</b>	<b>Very Good</b>	<b>Good</b>	<b>Only Fair</b>	<b>Poor</b>	<b>Don't Know</b>
In general, how well do you think our current health care system does in caring for dying people?	3	8	24	33	26	7
Making sure patients and their families are as involved as they want to be in decisions about care?	5	14	31	28	14	8
Making sure that dying peoples' wishes about their medical care are followed?	3	12	30	26	16	11
Making sure that dying people are as comfortable and pain-free as possible?	6	15	31	24	15	9
Providing emotional support to dying people and their families?	4	12	26	27	19	12
Respecting dying peoples' spiritual or religious beliefs?	6	16	32	21	13	12
Making sure families' savings are not wiped out by end-of-life care?	1	4	12	26	47	12

## MINNESOTA SURVEY RESULTS

Minnesota received grades of B in three categories of end-of-life care in the Last Acts survey (2002a). Minnesota state policies are supportive of effective advance care planning and provision of effective palliative care. In addition, Minnesota has a low rate of intensive care admissions of patients in their last six months of life.

However, many categories were graded D or lower. In particular, Minnesota residents were unlikely to be enrolled in hospice, especially in a timely fashion; were unlikely to die at home; and were unlikely to be in a hospital with specific hospice, palliative care or pain management programs. In addition, nearly 40% of nursing home residents experienced untreated or inadequately treated pain for at least two months.

Last Acts Survey of Minnesota's End of Life Care (Last Acts, 2002a)	Year	Score	Grade
State policies support good advance care planning	2002	3.5/5	B
State pain policies' level of support of palliative care	2001	6/ -3 to 9	B
Percentage of deaths occurring at home?	1997	23.7%	D
Percentage of deaths with hospice stays	2000	21.8%	D
Median length of stay in hospice (days)	2001	23.2	D
Percent of hospitals reporting pain management programs	2000	25.0%	D
Percentage of hospitals reporting hospice programs	2000	39.7%	D
Percent of hospitals reporting palliative care programs	2000	8.6%	E
Percent over 65 with 7+ ICU days during the last 6 months of life	2000	6.2%	B
Percentage of nursing home residents in persistent pain	1999	39.7%	C

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## ENSURING HIGH QUALITY END-OF-LIFE CARE

Because high quality, appropriate end-of-life care is not automatically provided in the American health care system, consumers must take responsibility for planning and directing their own end-of-life choices and the wishes of their loved ones. This must begin with advance planning through the state's legal documents relative to advance health care planning.

In Minnesota, the state's advance directive forms were found by Last Acts to be effective in planning for end-of-life care. Minnesota's Health Care Advance Directive allows Minnesota residents to choose one or two health care agents

who have the required statutory authority to make enforceable decisions for the individual completing the document. In addition, the individual can state specific treatments that s/he either wants or does not want in certain circumstances. The document is made legal by signing it in front of two witnesses or in front of a notary. Residents of Minnesota are urged to discuss their advance directive with their physicians and to provide copies to their agents, physicians, providers and attorneys. Copies of current advance directive forms and instructions for all states can be downloaded from [http://www.partnershipforaging.org/Advance/documents\\_content.html#mn](http://www.partnershipforaging.org/Advance/documents_content.html#mn).

Documents for each individual's state of residence should be used, and are generally considered valid if they are needed during travel to another state.

A second step people should take to ensure they receive the type of end-of-life care they prefer is to discuss this matter with their families, preferably before an emergency presents itself. Discussing end-of-life care in an abstract manner-absent a terminal diagnosis-can facilitate discussion and coping that becomes more stressful when a loved one is faced with a terminal condition. While facing issues of death and dying can be difficult, the failure to discuss these issues is one factor leading to inappropriate, expensive, and ineffective

terminal care. This type of discussion can be triggered as people review their estate plans; when new members are added to the family through birth, adoption, or marriage; or when family members are lost to divorce or death. Having a health care advocate to assist in discussion about end-of-life care and health care advance directives can be helpful to some individuals and families without experience in these matters or when there is family disagreement about end-of-life care and resuscitation issues.

A third step to facilitate appropriate end-of-life care is to choose a primary care physician who is open to discussion about the individual's desires and the wishes of their family members. All individuals should provide their physician with a copy of the advance directives and discuss, in advance, the general guidelines and preferences outlined in the document. It is

## PLANNING EFFECTIVE END-OF-LIFE CARE

- Write Advance Directive
- Discuss wishes with physician
- Choose a health care advocate
- Discuss wishes with family
- Enroll in hospice early

important to have a physician who is willing to support the individual's choices. In fact, if the physician is unable (for religious or other reasons) to support the end-of-life wishes of any patient, referral to another physician should be made. This is particularly important for individuals with a terminal diagnosis who are facing end-of-life care issues. These people can contact a local hospice organization, if necessary, to help identify physicians who are skilled in working with patients nearing the end of their lives.

The last major step in planning for effective end-of-life care is to enroll in a licensed, Medicare-certified hospice program in a timely manner. Most

hospice experts believe that patients receive the greatest benefit from hospice services if they participate for at least two months prior to death. However, on average, only one in five Minnesotans enrolls in hospice at all, and these people spend just over three weeks in a hospice program prior to death. These statistics mean that of the few who participate in hospice, most enroll at the "last minute." This lack of effective hospice use is responsible for many of the concerns and problems identified in the Last Acts surveys. Information about hospice and a provider search is available at <http://www.nhpc.org/custom/directory/?pageid=3257>.