

End-of-Life Care in Pennsylvania

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PREPARED BY

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EXECUTIVE SUMMARY

1. This background paper presents a broad overview of the current state of care for Pennsylvanians who are seriously ill and dying. Pennsylvania scored poorly on a national “report card” on the quality of end-of-life care in the 50 states, issued in 2002 by Last Acts, a national coalition to improve end-of-life care.
2. Pennsylvania’s low grades were based on low utilization of hospice care; the small percentage of Pennsylvanians who die at home rather than in institutions; inadequacies in the state’s advance directive policies; the small number of physicians and nurses certified in palliative care; the few hospitals with palliative care services; and the high percentage of nursing home residents reported to be in persistent pain.
3. Patterns of illness and causes of death in Pennsylvania have shifted dramatically from predominantly acute conditions and relatively rapid death around 1900, to predominantly chronic, long term, degenerative conditions today.
4. The current health care system evolved to provide care for acute illnesses, and is poorly equipped to provide coordinated, comprehensive care for people with chronic conditions, who can expect to live many years with varying levels of discomfort, disability, and dependency on others. Although palliative care and hospice are available to address the needs of critically ill and dying patients and their families, access to these services is uneven, and there are significant gaps in reimbursement mechanisms.
5. In addition to Pennsylvania’s high proportion of elderly, who are the majority of those with chronic, degenerative disease, a number of sub-populations in the state pose particular challenges to quality end-of-life care, e.g., children, racial and ethnic minorities, people with physical, cognitive, or developmental disabilities, and incarcerated individuals.
6. Despite a wealth of quantitative and descriptive data, there are many gaps in our knowledge about how people in Pennsylvania die. Improved data collection and research targeting statewide end-of-life practices and resources should be among the highest priority on the state’s end-of-life reform agenda.
7. States such as West Virginia, Oregon, and Michigan have created broad coalitions of stakeholders to improve end-of-life care through reform of professional and public education, legislation to improve advance directive policies, coordination of care across treatment settings, pain management, and quality assurance. Pennsylvania has an opportunity to learn from these states’ experience, and to adapt their models to the particular circumstances of our state.

I. Introduction

In 2002, the Robert Wood Johnson Foundation commissioned Last Acts, a national coalition to improve care and caring at the end of life, to prepare the report *Means to a Better End: A Report on Dying in America Today* (the “Means Report”).¹ This report was the nation’s first state-by-state “report card” on availability and use of care for dying Americans. The report issued all 50 states and the District of Columbia grades from A to E on eight key elements of end-of-life care (with A being the best possible grade and E the lowest). The elements of care that were graded included: state advance-directive laws; portion of deaths that occur at home; rate and duration of hospice use among the dying; access to hospital end-of-life care services; intensive care unit stays at the end of life; pain among nursing home residents; state pain management policies; and the numbers of doctors and nurses certified in palliative care.

Most states earned Cs, Ds, and Es on the majority of the measures. **Pennsylvania’s average score was a D.** On the positive side, Pennsylvania has established good state policies governing pain management, receiving a B. On the other hand, hospice use is low (only 21% of Pennsylvania residents over the age of 65 who die in Pennsylvania used hospice care in the last year of life); less than a quarter of Pennsylvania residents die at home, even though most Americans say they prefer to die at home; few Pennsylvania hospitals have palliative care programs to care for seriously ill and dying patients; the number of palliative care certified physicians and nurses is low and state advance directive policies are inadequate.

This background paper presents a broad overview of the current state of care for Pennsylvanians who are seriously ill and dying. Based on state and national statistics as well as the experience of practitioners, educators, researchers, patients, families and policy makers, the paper is intended to be a starting point for a statewide discussion about improving care for Pennsylvanians who are seriously ill and at the end of life.

The task is complex. There is no clear or agreed upon definition of who is “dying,” nor is there a consensus about clearly defined indicators to measure the quality of care at the end of life. Furthermore, data are difficult to obtain and are not available for most measures. The paper largely relies on data from national studies such as the Dartmouth Atlas on Health Care, the Brown Atlas on Dying, and the Means Report, since Pennsylvania-specific data are missing. This underscores the need for data specific to the care of Pennsylvanians at the end of life.

II. National Overview

A. Patterns of Mortality and Morbidity Have Changed Over the Past 100 Years

In the past century, there has been a dramatic shift in how Americans live and die. In 1900, an American’s life expectancy at birth was only 47.3 years² and most deaths were attributed to acute infectious causes. The three leading causes of death in the United States in 1900 were pneumonia, tuberculosis, and enteritis.³ Few people lived with chronic progressive illnesses and worsening disabilities. Advances in medical science in the past century have transformed this

trend completely. Today, the average life expectancy at birth is estimated at over 77 years² and most deaths are due to chronic progressive illnesses. The leading causes of death now include heart disease, cancer, and cerebrovascular diseases⁴. Other chronic conditions responsible for a significant number of deaths are diabetes mellitus, Alzheimer's disease, and chronic renal or liver disease.⁴ Almost half of those with chronic conditions have more than one.⁵ Death usually follows a prolonged period of progressive loss of function and numerous distressing symptoms, of which pain and shortness of breath are the most feared by patients, along with fear of the unknown. Because considerable medical technology now exists that can postpone death, costs are often high and most people die in hospitals or nursing homes, attended by strangers. For patients who die at home, the financial, physical, and emotional burdens of caregiving fall heavily on isolated nuclear families, and predominantly on women.

B. Health Care Systems Have Failed to Adapt to These Changes

The current health care system evolved to provide care for acute illnesses. It is poorly prepared to provide comprehensive, coordinated care for those with chronic conditions, especially for those near the end of life.⁶ Thus, a majority of patients with advanced or life-threatening illnesses continue to receive care in traditional acute care settings while the burdens of chronic illness are experienced mainly at home or in the community, over a long period of time. Our current health care system is guided by a medical model that focuses on treating disease, rather than focusing on quality of life for people with advanced illness. When acute, curative care fails, there is often an abrupt, poorly coordinated transition to supportive care services that emphasize comfort and quality of life. What is usually needed instead is a balance between these two earlier in the illness.

Medicare, the largest health insurance plan in the USA, is highly influential in end-of-life care because of the large number of beneficiaries who die each year. Furthermore, many commercial insurance plans look to Medicare when designing benefit structures for beneficiaries.⁷ The current health care system has primarily been created and designed along the types of care reimbursable by Medicare and other insurances. Medicare and other insurance programs' payment and coverage patterns serve their beneficiaries' needs for episodic interventions, such as surgery and diagnostic testing, rather than focusing on the needs of the chronically ill. Except in special programs like hospice, supportive services for long-term, eventually fatal, chronic diseases such as heart disease and dementia have not been central to financial or health care policies, precluding the design of good services for people who live with illness for extended periods of time before death.⁸

C. The Lack of Appropriate Systems of Care Makes the Experience of Dying Unnecessarily Burdensome

The landmark study sponsored by the Robert Wood Johnson Foundation (RWJF) in the mid 1990s, called the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT), uncovered many shortcomings in the quality of care received at the end of life.⁹ Based on analysis of data on several thousand critically ill, hospitalized patients at major academic medical centers, SUPPORT documented ineffective communication between patients and providers about care preferences, lack of advance care planning, and a high

prevalence of moderate to severe pain among dying patients. Building on this sobering report, investigators have filled in more details of the difficulties of modern dying, in the following areas.

1. Pain

The fear of pain at the end of life is a real concern for most individuals. Pain is one of the most common symptoms at the end of life, but is often managed inadequately, despite the ready availability of safe and effective treatments. Bonica¹⁰ found 70% of advanced cancer patients experienced pain, of whom 25% described the pain as severe, and 40% described it as moderate to severe. A major study in the outpatient oncology setting in 1994 found that 70% of the patients surveyed had been in pain the previous week.¹¹ Of those in pain, 36% reported pain severe enough to impair their ability to function. Despite the development of well-regarded pain guidelines in the 1990s, many physicians still do not adhere to standard pain relief guidelines and are reluctant to use opioids. Among the most significant impediments to the use of opioids for the effective treatment of pain are exaggerated concerns about addiction, respiratory depression and other side effects, society's stigmatization of drug use, and strict regulations aimed at preventing drug diversion.

2. Social and Financial Burdens

For many families, the diagnosis of a life-threatening illness of a family member is their first major confrontation with death. For family caregivers, the physical, emotional, financial, and social impact of providing care for a dying relative may be accentuated by social burdens such as restrictions on personal time, disturbance of routines, and diminished leisure time. A family caregiver may need to maintain a constant presence, becoming as housebound as the patient. There is potential for role conflict as the caregiver attempts to manage multiple responsibilities and forgoes his or her own needs in favor of those of the patient. Studies of the emotional consequences of caregiving reveal that relatives of cancer patients may experience as many, if not more, psychological problems than the patient.¹² These include anxiety, depression, reduced self-esteem, feelings of isolation, mental fatigue, guilt and grief. Data from the SUPPORT study revealed that financial burdens for families of severely ill patients are substantial, with 31% of families reporting loss of most or all of the family's savings, and 29% reporting the loss of the family's major source of income.¹³

3. Attention to Emotional Concerns

Patients who experience the transition from fighting their disease, to recognizing that conventional therapy is no longer effective, to accepting palliative care and possibly entering hospice, face challenges to their physical, emotional and spiritual integrity. Unfortunately, few physicians are prepared to discuss these transitions in a manner that meets the patient's needs. A study of terminally ill patients found that, depending on criteria used, between 13-26% suffered from depression.¹⁴ These symptoms often go unaddressed. For example, Goldberg and Mor¹⁵ found that only 3% of patients with terminal cancer were being treated with antidepressant medications, while internists have been found to recognize depression in only one-fourth to one-half of their depressed medical outpatients.^{16, 17, 18} Unaddressed adjustment and anxiety disorders

are also common among cancer patients and HIV-seropositive patients.^{19, 20, 21} Blanchard and Ruckdeschel²² state that most patients struggle with issues surrounding loss of control, the meaning of their illness, uncertainty about the dying process, and unfulfilled goals. Yet the majority of physicians fail to recognize emotional disorders in hospitalized patients who are both ambulatory and medically ill.^{23, 24} A study of 177 outpatient interactions in which oncologists gave bad news revealed that the physicians tended to use closed rather than open-ended questions, and only infrequently did they ask patients about psychosocial concerns.²⁵ Moreover, only one of the five oncologists could consistently predict patients' self-reported distress.²⁶

Physicians may view stopping treatment as a failure, or experience sadness at the anticipated loss of a patient, or they may simply lack the communication skills to convey empathy and respond to a patient's emotional needs. Without effective communication among patients, families and physicians, patients and family members often feel discouraged, abandoned, or pressured about care decisions.

D. Efforts to Meet the Needs of the Dying

1. Hospice and Palliative Care

The terms "palliative" and "hospice" care are frequently used interchangeably to describe an approach to the care for those who are likely to die in the relatively near future from serious, incurable diseases, and for whom the principal focus of care is quality of life and support for the patient's family. These terms gained currency in the last third of the twentieth century as a result of the changes in mortality and morbidity patterns detailed above. (The material in the following paragraphs is based on Doyle and Barnard.²⁷)

The "hospice movement," as it is popularly known, is generally agreed to have started in 1967 with the opening of St. Christopher's Hospice in London. Hospices were a feature of the Middle Ages in Europe, usually run by religious orders, and offered safety, healing, and rest to weary and often wounded travelers. It was therefore an obvious name to give to institutions founded in France, Ireland, and England around the turn of the nineteenth century to care for the dying. What made St. Christopher's and those that have followed it different was scientific rigor and professional education and training.

The word "hospice," though widely understood and accepted by the English-speaking world, was not universally acceptable because it had different, primarily religious, meanings in French and Spanish. Balfour Mount, who established a specialized unit at the Royal Victoria Hospital in Montreal in 1974 based on the principles he had learned at St. Christopher's, coined the term "palliative care" to circumvent the language problem. Because it was already in medical parlance, the term palliative care was accepted by the health care professions. Today, physicians working in this field describe themselves as palliative medicine physicians, nurses as palliative care nurses, and services where they work (the original hospices) as specialist palliative care services.

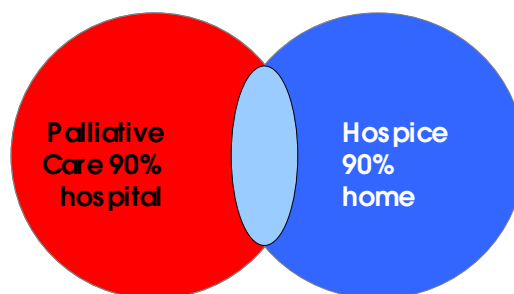
A good working definition of palliative care, which serves equally well for "hospice care," is that provided by Billings:

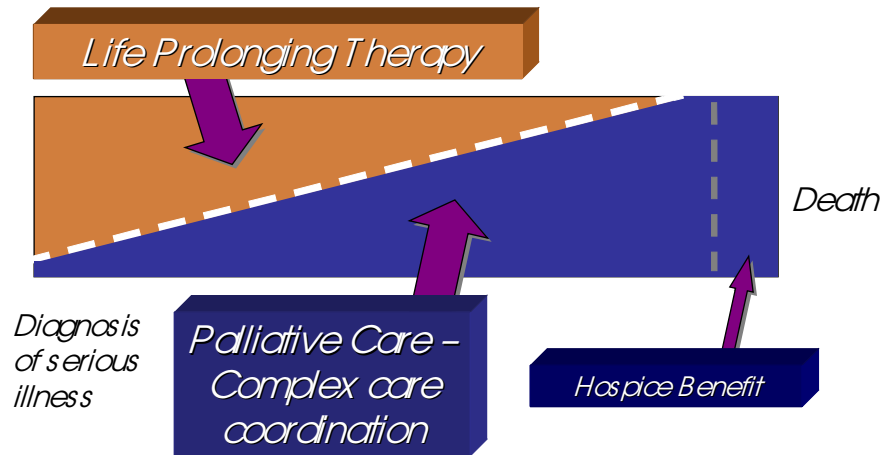
Palliative care is comprehensive, interdisciplinary care, focusing primarily on promoting quality of life for patients living with a terminal illness and for their families. Key elements for helping the patient and family live as well as possible in the face of life-threatening illness include assuring physical comfort, psychosocial and spiritual support, and provision of coordinated services across various sites of care.²⁸

As this definition suggests, palliative care can be provided at the same time as life-prolonging and disease-modifying therapies. No specific therapy is excluded from consideration. A goal of palliative care is to facilitate communication among the health care team, patient, and family to make sure that whatever medical treatments are offered to the patient reflect his or her values, quality-of-life preferences, and goals, and that they take into account family needs, beliefs, and culture.

Despite their similar philosophies and goals, “palliative care” has come to be associated primarily with services provided in the hospital, and at earlier phases of the patient’s illness, whereas “hospice care” is usually associated with care provided in the patient’s home. Hospice is also available in long-term care facilities and hospice inpatient units. Because most schemes of reimbursement for hospice require a patient’s life expectancy to be less than six months, hospice care has also come to be associated with the very last phase of illness.

The following diagrams show the overlap between the two forms of care. They highlight the problem for patients who would like to pursue treatment options, but also want palliative care.





Hospice care is covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations. Since the inception of the Medicare hospice benefit in 1983, the hospice industry has grown significantly, especially over the past five years. Presently, there are more than 3,200 accredited hospice programs that provide care to approximately 900,000 persons annually, or about 26% of all Americans who die.²⁹ Medicare spending on hospice has doubled since 2000 and now closely matches the dollars spent on the Medicare-supported end-stage renal disease dialysis program.³⁰ Although the number of beneficiaries with a non-cancer diagnosis is rising faster than those with cancer, cancer remains the most common hospice diagnosis. In 2000, 60% of Medicare beneficiaries who died of cancer used hospice services;³⁰ 50.5% of hospice admissions in the United States were cancer patients in 2002.²⁹

In contrast to community and home-based hospice care, hospital-based palliative care programs are a much more recent development in the United States. As recently as 1998, only 15% of U.S. hospitals reported having any services devoted to end-of-life care.³¹ In a survey of 5,810 member hospitals by the American Hospital Association in 2000, 13.8% of the 4,856 respondents reported having a palliative medicine service, while 22.7% reported a hospital-based hospice program, and 42% reported a pain management service.

Patients typically receive palliative care and hospice services late in the course of illness, even when they might have benefited from such comprehensive, interdisciplinary care much earlier. Currently, 30% of hospice patients died within one week of enrolling in 2000 compared to 21% in 1992.³⁰ The median length of stay for hospice patients in the United States has been dropping steadily for several years; the National Hospice and Palliative Care Organization reports that it was only 25 days in 2000. Under the Medicare fixed daily payment system, these short stays make it difficult for hospice programs to recoup the costs of admitting patients and providing

services so close to death. This creates a serious financial strain and minimizes the time hospice can provide services to the patient, caregivers, and families.

Although the reasons for widespread delays in referring patients and families to hospice and palliative care are still being investigated, it is likely that significant contributing factors include the difficulty of making precise estimates of life-expectancy—as is required for Medicare hospice eligibility—especially for diseases other than cancer;³² patients’ reluctance to accept the label “terminally ill”; the requirement that patients forego Medicare reimbursement for treatments with curative intent; and many physicians’ identification of a hospice referral with “giving up.”

2. Educational Efforts

Clinicians are often unprepared to manage the complex physical and psychosocial problems experienced by patients and their families at the end of life. Few health professionals are trained in palliative care and until very recently few medical schools and nursing programs included palliative care topics such as pain and symptom control, psychological and spiritual support, communication skills—including prognosis discussions, breaking bad news, and “do not resuscitate” (DNR) discussions—family conferencing, and ethics in their formal curricula. Additionally, recent studies revealed deficiencies related to end-of-life care in medical, pharmacy, and nursing textbooks.

In response to a growing concern about the quality of end-of-life care, improvements are being made in health professional education. Many medical schools are developing formal courses to better address the needs of dying patients. One of the more notable courses is the death and dying course for first year students at Harvard Medical School, where students accompany a patient through the last stages of illness over the course of a semester. A similar course is offered to medical students at the University of Pittsburgh. The American Medical Association has developed a training program that provides a curriculum for teaching physicians to care for terminally ill people and their families called Education for Physicians on End-of-Life Care (EPEC). The End-of-Life Nursing Education Consortium (ELNEC) is coordinating a similar national effort for nurses.

Medical students will now encounter questions related to palliative care on their National Board of Medical Examiners examinations, and the same is true for nurses who take the NCLEX (National Council Licensure Examination for Registered Nurses). Certification is now available in palliative care for physicians, and for nurses at both the basic and advanced practice level. Annual awards are now given to medical and nursing textbooks for end-of-life content.

E. Despite these Positive Signs, Barriers and Challenges Remain in Providing Good Care to People Near the End of Life

As described in the introduction, the Means Report is the nation’s first “report card” that grades states on their ability to provide end-of-life care. The intent of this project was for states to use the results as a “wake-up call” to citizens about the paucity of quality end-of-life care, and to highlight barriers to improvement. Section III of this paper highlights in detail Pennsylvania’s

grades in the Means Report. These indicators are a useful starting point for the state's self-assessment. Improvement in these categories should correlate with improved outcomes for Pennsylvanians with advanced, life-threatening disease.

As useful as the eight categories in the Means Report are, they are somewhat limiting. It would be a mistake to restrict the focus of Pennsylvania's Task Force on Quality at the End of Life only to the causes of Pennsylvania's low grades in these areas. A thorough assessment requires consideration of important barriers and challenges that are not directly addressed by the Means Report.

For example, the Coalition for Quality at the End of Life (CQEL), an organization based in southwestern Pennsylvania, uncovered additional factors that affect the quality of end-of-life care in a survey of physicians, other clinicians, long term care providers and community-based care providers. Among the most significant areas for concern identified by survey respondents were:

- Awareness of palliative care services on the part of health professional colleagues
- Control of pain
- Recognition and treatment of depression
- Communication between health professionals and between health professionals and families

Additional barriers stem from fragmented systems of care and reimbursement that fail to track the actual experiences of patients. For example, both national reports and the CQEL survey highlight the fact that services for people who are seriously ill and dying frequently follow funding streams, rather than following the needs of the individual. Insurance companies do not fund a full continuum of palliative care, nor do Medicaid or Medicare. Instead, services are reimbursed by settings, which often provide care in "silos" with poor coordination when patients move across settings.

A lack of community awareness of hospice and palliative care is as important as the gaps in professionals' knowledge of these services. The CQEL report and work done by the Take Charge Partnership of Western Pennsylvania have shown that there is not enough education being given to consumers and families, with the result that many people do not even know about palliative care services or hospice, much less feel empowered to insist on state-of-the-art treatment of physical symptoms or help with psychosocial and financial problems.

III. The End-of-Life Experience for Pennsylvanians

A. The Experience of Pennsylvania Highlighted by the Means Report

The following table summarizes the grades Pennsylvania received in the eight areas analyzed nationally in the Means Report:

End-of-Life Care in Pennsylvania

Criteria	Measure	Grade
State Advance Directive Policies: <i>Do state policies support good advance care planning?</i> Quality of state advance directive laws, 2002	1.0 on a scale of 0 to 5	E
Location of Death: <i>What proportion of the state's deaths occur at home?</i> Percentage of state residents who died at home, 1997	23.2	D
Hospice Use: <i>Is hospice care widely used in the state?</i> Percentage of deaths with hospice stays, 2000 Median length of stay in hospice (days), 2001	21.2 24.3	D D
Hospital End-of-Life Care Services: <i>Do the state's hospitals offer pain and palliative care services?</i> Percentage of hospitals self-reporting pain management programs, 2000 Percentage of hospitals self-reporting hospice programs, 2000 Percentage of hospitals self-reporting palliative care programs, 2000	57.6 30.3 21.7	C D D
Care in ICUs at the End of Life: <i>How many elderly people spend a week or more in intensive care units during the last six months of life?</i> Percentage of state residents over 65 with seven or more ICU days totaled across all admissions during the last six months of life, 2000	11.5	C
Pain Among Nursing Home Residents: <i>How well do the state's nursing homes manage their residents' pain?</i> Percentage of nursing home residents in persistent pain, 1999	38.8	C
State Pain Policies: <i>Do state policies encourage good pain control?</i> State pain policies' level of support of palliative care, 2001	7 (on a scale of -3 to 9)	B
Palliative Care-Certified Physicians and Nurses: <i>Does the state have enough physicians and nurses who are trained and certified in palliative care?</i> Percentage of primary care and primary care subspecialty physicians who are certified in palliative care, 2000 Percentage of estimated number of full-time equivalent registered nurses who are certified in palliative care, 2000	0.19 0.46	D C

Effective strategies to improve Pennsylvania's grades must reflect the actual circumstances of our population. Therefore, the next sections of this paper analyze in more detail the end-of-life

experience of Pennsylvanians, beginning with a demographic overview and proceeding to a survey of needs and challenges for various subsets of the population.

B. Demographics of Pennsylvania

Death occurs in all age groups, but nationally and in Pennsylvania it occurs most frequently among older people. Nationally, 70% of the deaths each year occur among people age 65 and older; in Pennsylvania that figure is 78%. Consequently, though this report will address all age groups, it is important to emphasize that end-of-life issues are particularly urgent in Pennsylvania because of its aging population.

Currently, people age 65 and older comprise 15% of Pennsylvania’s total population (compared to 12% in the U.S.) (See Table 1). This number is expected to grow. Most baby boomers (those born between 1946 and 1964) are now in their fifties, and for the most part they are healthier than earlier generations. They can expect to live well into their seventies and eighties.

It is estimated that one in five U.S. citizens will be elderly by 2030. Of this group, the oldest old (age 85 and over) are projected to double to 7 million by 2020.³³ It is expected that Pennsylvania’s aging trends will mirror that of US Census Bureau projections (see Table 2 and Table 3). By the year 2025, the population of Pennsylvania is expected to reach an estimated 12,683,000.³⁴ By 2025, Pennsylvania is expected to rank 5th in the proportion of elderly among all the states.³⁵ These demographic transitions pose significant challenges for the aging, their families, and the health care system at large.

Table 1.
Population Distribution of Pennsylvania Compared with the U.S. (2003).³⁶

Age Cohort	PENNSYLVANIA		UNITED STATES	
Children ≤18	3,026,540	25%	77,597,590	27%
Adults 19-64	7,283,470	60%	175,111,560	61%
65+	1,853,830	15%	34,659,260	12%
65-74	992,580	8%	18,238,320	6%
75+	861,250	7%	16,420,940	6%
Total	12,163,850	100%	287,368,410	100%

Table 2.
Projection of the Total Population (in Thousands) of Pennsylvania and United States.³⁴

Year	2005		2015		2025	
United States	285,981	100%	310,133	100%	335,050	100%
Pennsylvania	12,281	4.29%	12,449	4.01%	12,683	3.79%

Table 3.

Pennsylvania Population Projection by Age Cohorts (2005- 2025).³⁷

Ages	2005		2015		2025	
	0-4	730	6%	747	6%	750
5-17	2,115	17%	1,991	16%	2,034	16%
18-24	1,116	9%	1,116	9%	1,045	8%
25-64	6,453	53%	6,503	52%	6,195	49%
≥ 65	1,867	15%	2,092	17%	2,659	21%
Total	12,281	100%	12,449	100%	12,683	100%

C. How People Die

According to the Pennsylvania Department of Health, Bureau of Health Statistics and Research, 128,890 Pennsylvanians died in 2003.³⁸ The five leading age-adjusted causes of death were heart disease (29%), cancer (23%), stroke (6%), chronic lower respiratory disease (5%), and accidents (4%). Table 4 is the breakdown of causes of death by age group for Pennsylvania residents.

Table 4.

Under 5 Years of Age	5-24 years of Age	25-44 Years of Age	45-64 Years of Age	65 Years and Older
Perinatal conditions	Accidents	Accidents	Cancer	Heart Disease
Birth Defects	Assault (Homicide)	Cancer	Heart Disease	Cancer
Accidents	Suicide	Heart Disease	Accidents	Stroke
Assault (Homicide)	Cancer	Suicide	Diabetes Mellitus	Chronic Lower Respiratory Disease
	Heart Disease	Assault (Homicide)	Stroke	Diabetes Mellitus
.95% of all PA deaths	1.3% of all PA deaths	4.2 % of all PA deaths	14.6 % of all PA deaths	78.8% of all PA deaths

The leading causes of death in Pennsylvania mirror the national experience reported in the Institute of Medicine Report³⁹ and disproportionately affect older people. Medical treatments make it possible to live longer with these diseases, but the care is often intensive, prolonged, and costly. The chronic nature of these conditions makes it difficult to determine prognosis. This

prognostic uncertainty is a barrier to timely transitions to palliative and hospice services, and may also help explain the data in the next section on the most common locations of death.

D. Where People Die

1. Hospitals

As discussed above, over the last century, death has moved out of homes and into institutions such as hospitals, nursing homes and personal care homes.³⁹ The Means Report used both death in the hospital and death in the ICU as indicators of poor quality, assuming that higher rates of hospitalized deaths translate into poor end-of-life experiences for most Americans.

While nine out of ten Americans say they would prefer to die at home, in 2001 US mortality statistics showed that about 49.5% of all deaths occurred in hospitals, 17% in nursing homes, 20% in residences (homes, personal care homes, assisted living, etc.) and 6% elsewhere. In Pennsylvania, about 49% of deaths occur in the hospital, 27.7% occur in nursing homes, and 23% occur at home. Moreover, 20% die after receiving the most technologically advanced care available while in an intensive care unit.⁴⁰

The apparent contradiction between people’s expressed preferences about the location of death and what actually happens to them may be explained in part by the uncertainty surrounding predictions of time of death, especially in acute-care settings where advanced technology is used to prolong life. People may also answer “at home” in opinion surveys as a way to describe their general hope of being free from physical and emotional suffering and in a familiar setting. Death in the hospital or death in the hospital ICU is thus often used as a proxy for poor quality end-of-life care, when that may not always be the case.

National studies, such as the Dartmouth Health Care Atlas (www.dartmouthatlas.org), have demonstrated that site of care and site of death vary considerably across the county. For example, in 2001, 31% of Pennsylvania Medicare beneficiaries died in the hospital, 18% either died in an intensive care unit or were admitted to the ICU during the hospitalization in which death occurred. By contrast, in Oregon, only 23.5% of Medicare beneficiaries die in hospitals and of those, only 12 % are in the ICU during their final hospitalization. For older Pennsylvanians, the average number of hospital days during the last six months of life is 11.8, compared to only 6.2 for older Oregonians.

Table 5.

Adjusted site of death of Pennsylvanians (in percents).

	1989	1997	2001
Hospital	61.4	49.0	46.5
Nursing Home	20.0	27.9	30.3
Home	17.2	21.5	21.4

Source: Brown Facts on Dying (www.chcr.brown.edu/dying/paprofile.htm)

Table 5 shows that the trend for site of death in Pennsylvania is slowly shifting out of the hospital. Beyond the proportion of in-hospital deaths, however, is the quality of care that dying people receive in the hospital. Given that there is no consensus on what percentage of people should appropriately spend a week or more in an ICU in the last six months of life, the measure that was used in the Means Report was graded on a curve. The higher-ranking states had lower percentages of Medicare patients who spent a week or more in the ICU in their last six months of life. States ranged between 3% and 17%. Five states where the ICU rate was under 6% received an A. Most states rated a C; between 8% and 12% of Medicare patients stayed a week or longer in the ICU during the last six months of life.

On this indicator, Pennsylvania received a C for the percentage of state residents over the age of 65 with seven or more ICU days during the last six months of life.

The Means Report also looked at the percent of hospitals reporting pain management programs, the percent of hospitals reporting hospice programs, and the percent of hospitals reporting palliative care programs. States were placed into one of five groups, with the better states having the most hospitals that offer formal end-of-life care services. No state earned an A; most states received a C. Nationally, about 14% of hospitals offered a formal palliative care program, 23% offered hospice care, and 42% had pain-management programs.

Pennsylvania received a C on its hospitals reporting pain management programs (57%), and it received D scores for the number of hospitals reporting hospice programs (30%) and palliative care programs (21%).

2. Nursing Homes

While the trends both nationally and in Pennsylvania show that fewer people are dying in hospitals, more people are dying in nursing homes. Today, one-quarter of Americans die in nursing homes. From 1997 to 2001, there was a 1.6% increase in the number of Pennsylvanians dying in nursing homes. Brown University researchers reported in a 2002 study that by 2020, 40% of deaths that will occur in nursing homes.

In most nursing homes it is difficult for the facilities and their staff to make the transition from rehabilitating elderly patients to preparing them for death. The difficulty stems partly from strict regulation of nursing homes that can appear to administrators as limiting options near end-of-life; partly from lack of resources and funding; and partly from our culture's reluctance to accept death.⁴¹

Recent studies have demonstrated that end-of-life care in nursing homes often results in unnecessary suffering due mainly to a lack of staff time, training, and communication. In the Means Report, pain among nursing home residents was measured as part of the state's pain policies. In this category, an A was reserved for states where fewer than 25% of nursing home residents reported being in pain for at least two months without relief. No state received an A. Most scored a C; between 35% and 45% of nursing home residents in these states were in persistent pain.

Pennsylvania was one of 39 states to receive a score of C in this category.

3. Hospice Use

Many end-of-life experts, as well as patients and families, consider hospice to be the “gold standard” in end-of-life care in terms of both quality and cost effectiveness. Given this consideration, measuring hospice use and the length of stay in hospice at the end of life is often used as a proxy for quality end-of-life care.

In the Means Report, the Last Acts investigators reserved the top grade for hospice use for states where more than 50% of elderly people used hospice in their last year of life. No state scored an A. The only B was given to Arizona, where hospice use was 42%. Most states received a D, with 12% to 25% of all elderly deaths involving hospice.

In the category of length of stay in hospice, an A was reserved for states where the median hospice length of stay was 60 days. No state achieved an A or a B. Most received a D, with median length of stay between 15 and 30 days.

Pennsylvania received a D grade in both categories, with only about 21% of all deaths for people over the age of 65 occurring while in hospice care, with a median length of stay of about 24 days.

4. Death at Home

Death at home is often used as a proxy for quality end-of-life care and has become synonymous with a “good death.” But death at home may not be a “good death” if it was accompanied by overwhelming physical symptoms, anxiety, and insecurity or by severe financial hardship for the patient and family. If, on the other hand, death at home included the provision of excellent symptom control, as well as emotional, spiritual, and social support, it may be a valid indicator of quality end-of-life care.

With this qualification in mind, in the Means Report the top grade for deaths occurring at home was reserved for states where more than 60% of deaths occurred at home. No state earned an A or a B in this category. Most scored a D; in these states, between 15% and 30% of deaths occurred at home.

In Pennsylvania, less than one quarter (23%) of state residents die at home. Pennsylvania earned a D grade for this indicator.

E. Special Populations

1. Children

Children who are seriously ill and at the end of life have problems that set them apart from the adult population. In the U.S., 75,000 – 100,000 children die each year, and approximately 1 million children are seriously ill with a life-threatening condition.⁴² In Pennsylvania, 2003

Bureau of Health Statistics and Research data reported 1,222 deaths between ages 0 and 4; 104 deaths between ages 5 and 9; 146 deaths between ages 10 and 14; and 562 deaths between ages 15 and 19—for a total of 2,042 deaths for this segment of the population. Pennsylvania data are not available for children seriously ill with life-threatening conditions.

Many children who die are born with rare medical conditions that create substantial uncertainty in diagnosis, prognosis and medical management. Even for common medical problems, children's general resiliency complicates predictions about their future. In situations laden with fear and anxiety, this greater uncertainty adds to the burdens on physicians and families as they try to assess the potential benefits and harms of treatment options. Many communities may not have enough cases of various life-threatening medical conditions in children to generate much local experience and clinical expertise, including familiarity with good pediatric end-of-life care. As a result, seriously ill children and their families must often travel far from home for treatment, which removes them from their usual sources of emotional support and may disrupt parents' employment. Family relationships and finances can suffer under the strain.

Unlike virtually all older adults who are covered by Medicare, approximately 15% of children lack public or private health insurance. Medicaid is by far the largest provider of children's health insurance. More than half of all Medicaid enrollees across the country are children and more than a quarter of Pennsylvania's children are enrolled in Medicaid. Children with insurance are covered by a myriad of private and state programs that offer palliative, end-of-life, and bereavement services. On one hand this diversity of insurance sources could encourage innovation, while on the other hand, it makes it extraordinarily difficult to identify and correct deficiencies in any comprehensive way.⁴²

2. Older Adults

Most Americans can expect to live a long life and die at an old age. In 1995, the estimated life expectancy reached 75.8 years. Women can now expect to live nearly 80.1 years, and men almost 74.8 years. Of those American women who reach 75 years of age, they can expect to live, on average, 12.7 additional years, while men can expect to live 10.6 years longer.⁴

The fastest growing segment of the population in the United States and in the state of Pennsylvania are residents 85 years and older. In 2002, Pennsylvania residents 85 years and older were 1.8% of the total population, yet this group accounted for 30% of all deaths in the state. For the age group 85 and over, 37.7 % of all the deaths were from diseases of the heart, compared to 11.7% from cancer, 9.4% from cerebrovascular disease or stroke, and 4.4% from Alzheimer's disease.³⁸

Death in the very old is generally viewed not as dying from a specific pathology but from an accumulation of age-related deteriorations—those conditions that have an increased incidence with longevity. Only recently has palliative care been recognized as important for the frail elderly living in nursing homes or personal care homes, yet there is great potential for relieving symptoms of a distressing physical nature, particularly chronic pain.

3. Minorities

Minorities comprise over 16% of Pennsylvania’s population (see Table 7). Imparting effective palliative care to minorities and their families may pose specific challenges stemming from factors such as cultural or religious differences, diverse health beliefs, and access to health care during serious and advanced illnesses.

African Americans and Hispanics report difficulty locating a “usual source” of medical care and use more emergency services for advanced illnesses in the last year of life.⁴³ They are more likely than whites to report using outpatient services and emergency rooms as their usual source of care^{44, 45} and are more likely than whites to die in the hospital.^{46, 47} Surprisingly, these trends are not only limited to uninsured individuals but also for those with public health insurance.^{45, 48} This was underscored in the IOM report that stated that “geographic availability of health care institutions...largely... influenced by economic factors...may have a differential impact on racial ethnic minorities, independently of insurance status.”⁴⁴

An emerging body of literature suggests that costs of care in the last 12 months of life are actually higher among African Americans when compared to whites,⁴⁹ even though African Americans remain disadvantaged in their access to effective treatments and other healthcare services in the last few months of their lives.^{44, 50} It is speculated that the increased cost of healthcare among minorities is attributed to patterns of care utilization and care preferences at the end of life. For instance, many African Americans equate palliative care with “abandoning of hope.”⁵¹ With their history of legitimate distrust of the health care system, many African Americans worry that their socioeconomic and racial status will make them more “disposable.”⁵⁰ This concern may be reflected in decisions to continue aggressive treatments even when medical benefit is unlikely. Similarly, African Americans are less likely to enroll in a hospice program than whites.⁵² Of the 885,000 patients served by U.S. hospices in 2002, only 9.2% were African Americans⁵³ (see Table 6). African Americans are also more likely than whites to prefer aggressive treatment during the final phase of life. Some studies have found that African Americans more often request life-sustaining interventions such as cardiopulmonary resuscitation, mechanical ventilation, and tube feeding.^{54, 55, 56, 57} Similarly, the caregivers of African-American patients are less likely to sanction withholding life-sustaining treatment at the time of death and are less accepting of their relatives’ death.⁵⁸

Efforts to improve end-of-life care for minorities should be geared towards improving access and continuity of care, designing culturally sensitive models of palliative care, and making the resources that palliative care offers for improved quality of life more acceptable.

Table 6.
Racial /Ethnic Characteristics of Patients Served by Hospice (2002).²⁹

White or Caucasian	Black or African American	Hispanic or Latino	Asian or Hawaiian/Pacific	Multiracial
82%	9.2%	4.3%	0.8%	3.7%

Table 7.

Population Distribution of Pennsylvania by Race/Ethnicity (2003).³⁶

<i>Race</i>	PA #	PA %	US #	US %
White	10,196,710	83.8	194,236,600	68
Black	1,169,690	10	34,809,870	12
Hispanic	477,230	4	40,322,930	14
Other	320,220	3	17,999,010	6
Total	12,163,850	100	287,368,410	100

4. Individuals with cognitive, intellectual, or developmental disabilities

The concept of “disability” is very broad, and can encompass physical, cognitive, intellectual, and developmental issues. Because every person is unique in his or her personal, social, and environmental circumstances, it is impossible to generalize about such a diverse population. Many Pennsylvanians with physical and mental disabilities live independently in their homes and communities, often with the help of state programs. Indeed, more people are residing in the community than in institutions.

People with chronic disabilities are likely to confront important challenges related to end-of-life care. Certain guiding principles should be kept in mind:

- Self-determination is for everyone.
- Everyone can make choices.
- Everyone should have control over his or her life/end-of-life issues.
- Everyone is different and there is value in difference; therefore end-of-life issues need to be individualized.

Advocates for the disabled frequently express concern that a focus on “dying well,” and on avoiding intensive care for people who are seriously ill, will reinforce negative stereotypes of disabled people, and make them more vulnerable to premature conclusions about poor quality of life, and to withholding resources. For people who cannot communicate, or who rely on paid caregivers and substitute decision makers, choices about medical treatment can by-pass the affected individual’s self-determination.

Unfortunately, there is very little data to help us determine whether people with disabilities actually suffer from these difficulties when they are seriously ill. One goal for the Task Force should be to investigate these issues further, and collect data so we can get a more accurate understanding of what problems people with disabilities face. This will be particularly important to insure that any solutions to the public policy issues related to end-of-life care take into account potential discriminatory impacts on vulnerable individuals or groups.

5. Incarcerated Individuals

As the prison population ages, the Department of Corrections frequently must address end-of-life issues relating to inmates who have spent most of their lives in prison with little hope of returning to society. In 2003, 1% of all Pennsylvania deaths occurred in state prisons. The top five causes of deaths for Pennsylvania prisoners are listed in Table 8.

Table 8.

Source: Pennsylvania Department of Corrections

Cardiovascular Disease	43%
Cancer	21%
Liver Disease	7%
Renal Failure	6%
Suicide	4%

These conditions are often undiagnosed or under-treated prior to incarceration, and inmates are often admitted with advanced or end-stage disease. A 50-year-old inmate may have the health status of a non-incarcerated individual who is 10 years older. Older inmates also have increased morbidity and mortality from chronic diseases such as diabetes, cardiovascular disease, renal disease, and pulmonary disease. As prison sentences have become longer, thousands of frail, sick and elderly inmates are awaiting death behind bars. Providing quality end-of-life care in prisons is complicated by a myriad of problems including lack of palliative care training, lack of availability of opioids, and unique spiritual concerns of inmates at the end of life.

In 2002, the General Assembly asked the Joint State Government Commission to establish an Advisory Committee on Seriously-Ill and Geriatric Inmates to study problems unique to older and infirm inmates in the state correctional institutions. The committee includes criminal justice and health experts from both in and out of government. It is expected to issue its report later this year. As part of its study, the committee toured the State Correctional Institution at Laurel Highlands, a special institution operated by the Department of Corrections to house long-term care, wheelchair-bound, and geriatric male inmates. The facility provides specialized programs that meet the needs of geriatric and seriously ill inmates; for example, medical care for long-term illness, life skill programs, and recreational activities that are individualized to meet the needs of older or physically challenged inmates. Plans are under way to increase skilled beds at Laurel Highlands in 2006. The advisory committee also toured the State Correctional Institution at Muncy that provides many of the same services for incarcerated women. Additional capacity for assistive living (personal care) is also planned for the State Correctional Institution at Waymart in 2005.

F. State Law, Regulations and Policies

State laws, regulations, and policies affect many aspects of the experience of serious illness and end-of-life care. While a comprehensive analysis of their impact exceeds the scope of this background paper, we will look at three broad areas that represent some of the most significant concerns of people who receive end-of-life care and those who provide it: (1) respecting

preferences for medical treatment; (2) keeping people comfortable by alleviating pain and other distressing symptoms of advanced disease; and (3) paying for care.

1. Respecting Treatment Preferences

Attention has recently focused on the Florida case of a 41-year-old woman, Terri Schiavo, whose parents and husband engaged in 15 years of litigation over whether she was at the end of her life and the kind of treatment she would want at the end of her life. Advance directives are intended to enable people to make their wishes known to their family and health care providers, even when they are unable to communicate at the time decisions must be made. In the Means Report, states were measured on the extent to which state advance-care directive laws were clear, comprehensive, and easy to use. Pennsylvania's statutes that relate to decision making for incompetent or otherwise nonautonomous patients are summarized in the following table.

Table 9.

State Laws Related to Medical Decision Making Near the End of Life.

Probate, Estates and Fiduciaries Code, Title 20 Pennsylvania Consolidated Statutes
<p>Chapter 54 addresses advance directives for health care, more commonly referred to as living wills. Through a living will, a person may direct his physician to initiate, continue, withhold or withdraw life-sustaining medical treatment when the person becomes incompetent and is in a terminal condition or permanently unconscious. Chapter 54 includes a sample living will form.</p>
<p>Chapter 54A provides for out-of-hospital do-not-resuscitate orders. A person with a terminal condition may wear a bracelet or necklace supplied by the Department of Health indicating that a physician has issued a do-not-resuscitate order and that emergency medical services providers should not try to resuscitate the person. Chapter 54A contains a form for the out-of-hospital do-not-resuscitate order.</p>
<p>Chapter 55 authorizes guardianships of incapacitated persons. The law is frequently used when children of aging parents need to obtain legal authority to make personal care and financial decisions when their parents are no longer capable of doing so. There is a preference for limited guardianships so that a partially incapacitated person may make as many personal decisions as possible.</p>
<p>Chapter 56 provides for powers of attorney. Through a power of attorney, a competent person, the principal, may grant certain powers to an agent such as the power to handle the principal's financial matters or make health care decisions. Powers of attorney are presumed to be durable, i.e. exercisable even when the principal is subsequently disabled or incapacitated. Chapter 56 includes a list of powers that may be included in a power of attorney.</p>
<p>Subchapter "C" of Chapter 58 (effective January 31, 2005) provides Mental Health powers of attorney for competent adults to direct their future mental health care through designation of an agent, and includes the principal's preference for a guardian should one be needed in the future.</p>

The Means Report analyzed state laws according to the following *general* criteria:

- Laws should recommend a single, comprehensive advanced directive, reducing confusion.
- Laws should avoid mandatory language, to allow freedom of individualized expression.
- Laws should give precedence to the authority of the agent or most recent directive over the living will.
- Laws should specify default surrogates if the patient has not named someone.
- Laws should include “close friend” when listing potential surrogates, rather than restricting available surrogates to “family.” (In Pennsylvania, “close friends” are allowed to be powers of attorney.)
- Laws should provide a statewide non-hospital DNR order for Emergency Medical Personnel. (Pennsylvania has a law that provides for out-of-hospital do-not-resuscitate orders.)

Based on these criteria, seven states received an A, and twelve states rated a B. Most states (18) received a C. Pennsylvania, whose current law clearly meets the second criterion, was one of four states to receive an E—the lowest possible grade.

2. Keeping People Comfortable

Physicians’ ability to prescribe and administer pain relieving medications to patients with advanced, life-threatening disease can be adversely affected by state laws regulating the use of controlled substances, which include opioid medications such as morphine. The Means Report evaluated state pain policies according to whether the policy:

- Explicitly addresses the needs of terminally ill patients.
- Adopts model pain treatment guidelines of the Federation of State Medical Boards.
- Includes provisions with the potential to impede prescribing pain medication.
- Reassures physicians that they can treat pain with opioids without undue regulatory scrutiny.
- Defines what constitutes good medical practice for pain management.
- Expresses concern about the undertreatment of pain.

Pennsylvania received a B, its highest score in this category. Most states fell in the C and D range. An important document that reflects a relatively supportive regulatory climate for pain management in Pennsylvania is “Guidelines for the Use of Controlled Substances in the Treatment of Pain,” adopted October 20, 1998, by the State Board of Medicine. It is adapted from the model guidelines proposed by the Federation of State Medical Boards. The key language in this document reads:

Physicians should not fear disciplinary action from the Board or other state regulatory or enforcement agency for prescribing, dispensing, or administering controlled substances, including

opioid analgesics, for a legitimate medical purpose and in the course of professional practice. The Board will consider prescribing, ordering, administering, or dispensing controlled substances for pain to be a legitimate medical purpose if based on accepted scientific knowledge of the treatment of pain and in compliance with applicable state or federal law.

The Board will judge the validity of prescribing based on the physician's treatment of the patient and on available documentation, rather than on the quantity and chronicity of prescribing. The goal is to treat the patient's pain for its duration while effectively addressing other aspects of the patient's functioning, including physical, psychological, social, and work-related factors.

3. Paying for Care

The burdens of living with life-threatening or incurable illness are physical, psychological, spiritual, social, and financial; require a multidisciplinary approach to providing care; and occur in a variety of settings (e.g., hospital, home, nursing home, inpatient hospice). Consequently, payment mechanisms are complex. Physicians, nurses, home health aides, therapists of various types, pastoral care, social workers, personal and custodial care, and acute hospital care, for example, could all be involved over the course of a person's final illness, and during the family's period of bereavement. The various sources of third-party reimbursement—state and federal government programs such as Medicare and Medicaid or the Veterans Administration, commercial plans such as Capital Blue Cross or Highmark Blue Shield in Pennsylvania, health maintenance organizations—all have their own criteria for what services to cover, and at what rate.

Since 1983, the Medicare Hospice Benefit has served as a kind of template for a bundle of services for which patients may be eligible, once their physician certifies that the patient's life expectancy is six months or less. The Medicare Home Health Benefit, which does not have the six-months-or-less requirement, is also an important funding source, and, like the Hospice Benefit, sets the pattern for a number of other payment systems, such as Medicaid and many commercial insurers.

The following information, prepared for consumers by the Initiative for the Terminally Ill on Medicare (ITIM), summarizes the covered services and eligibility requirements of the Medicare Home Health and Hospice Benefits:

MEDICARE HOME HEALTH BENEFITS	
Eligibility	Coverage
<p>To get help from Medicare, you must:</p> <ul style="list-style-type: none"> • Have Medicare Part A or B • Be homebound • Need help from a skilled nurse or a skilled therapist less than seven days a week or daily for a specific length of time. <p>You can get help even if you have not been in a hospital. You can also get help whether you have a short-term or long-term condition.</p> <p>You cannot get help for home health aide services like cooking and bathing unless you also need skilled services.</p>	<p>The home health benefit will pay for:</p> <ul style="list-style-type: none"> • Skilled nursing services on a part-time (less than 8 hours per day) or intermittent (less than 7 days per week) basis • Skilled therapy services • Home health aide services • Medical social services • Approved medical supplies used by home health agency staff <p>The amount of care Medicare will pay for depends on how sick you are. If you qualify, Medicare will pay for a maximum of 35 hours per week of total skilled nursing and home health aide services in addition to therapy services.</p>

To Get the Medicare Home Health Benefit

- Your doctor must state that you meet the requirements for eligibility. Your doctor should also state the kind of skilled services you need and how often you will need them.
- A Medicare-Certified Home Health Agency (CHHA) will send a nurse to decide your plan of care.

How to Get the Medicare Hospice Benefit

- Two doctors must agree that you are eligible.
- A Medicare-approved hospice will send a nurse to decide your plan of care.
- You must sign a statement giving up standard Medicare coverage for your terminal illness and treatments for curing your terminal illness.

Source: Medicare Rights Center, Initiative for the Terminally Ill, <http://medicarerights.org/maincontentitimhleaflet.html>, accessed May 11, 2005.

MEDICARE HOSPICE: ELIGIBILITY

To get help from Medicare hospice:

- You must have Medicare Part A
- Your doctor and the hospice medical director must agree that you have a life expectancy of less than six months
- You must agree in writing not to want treatments for curing your illness

You do not need to wait until your condition is very bad or you are in a medical crisis to qualify.

MEDICARE HOSPICE: COVERAGE

Medicare will pay for the following services in full:

- Skilled nursing services
- Doctor services
- Skilled therapy
- Home health aide services
- Medicare social services
- Spiritual counseling
- Medical supplies
- Nutrition and other counseling

Medicare will not usually pay for 24-hour care. The amount of care Medicare will pay depends on your health status. During a medical crisis, you may be able to get continuous nursing services at home or care in a hospital, skilled nursing facility or the hospice's inpatient unit.

The hospice benefit also covers nearly all of the cost of:

- Drugs to take care of your pain and your symptoms
- Inpatient respite care to temporarily takeover the caregiving responsibilities of families

Medicare will pay for care from your own doctor even if he or she is not a hospice employee.

You may be able to get continuous nursing services at home or care in a hospital, skilled nursing facility or the hospice's inpatient unit.

The hospice benefit also covers nearly all of the cost of:

- Drugs to take care of your pain and your symptoms
- Inpatient respite care to temporarily takeover the caregiving responsibilities of families

Medicare will pay for care from your own doctor even if he or she is not a hospice employee.

The following information specifically about state support for hospice care in Pennsylvania was provided for this background paper by the Departments of Public Welfare, Health, Corrections, Insurance, Aging, Military and Veterans Affairs and the Pennsylvania Employees Benefit Trust Fund (PEBTF):

The Office of Medical Assistance in the Department of Public Welfare follows the Medicare template for covered services and payment rates for hospice care in its fee-for-service program. Expenditures were approximately \$4 million in 2003-2004. Managed care organizations contract with hospice organizations and pay for services at a negotiated rate. Their expenditures totaled approximately \$5 million in 2003-2004.

Regulations pending and currently under final-form review by the Independent Regulatory Review Commission and committees in the state House and Senate would permit hospice services to be provided in a personal care home.

Under the OBRA and Independence Home and Community Based Waiver programs for people with developmental and physical disabilities, respite care is available in the case of absence or need of regular care providers on a short-term basis. Respite expenses for 2002-2003 (the last year for which data are available) were \$218,708 for OBRA and \$1,380,949 for Independence.

Finally, the Pennsylvania Employees Benefit Trust Fund (PEBTF) includes a Hospice Benefit, modeled closely on the federal Medicare Hospice Benefit. The PEBTF coverage is summarized as follows:

Covered Palliative and Supportive Services

- Professional services of an RN or LPN
- Physician fees (if affiliated with the Hospice)
- Therapy services (except for dialysis treatments)
- Medical and surgical supplies and Durable Medical Equipment
- Prescription drugs and medications
- Oxygen and its administration
- Medical social services consultations
- Dietitian services
- Home Health Aide services
- Family counseling services

Special Exclusions and Limitations

The PEBTF Hospice Care Program must deliver hospice care in accordance with a Treatment Plan approved by and periodically reviewed by the Claims Payor.

No Hospice benefits will be provided for:

- Medical care rendered by your physician
- Volunteers, including family and friends, who do not regularly charge for services
- Pastoral services
- Homemaker services
- Food or home delivered meals

- Hospice inpatient services except for Respite Care

Respite care is limited to a maximum of ten days of facility care or 240 hours of in-home care throughout the treatment period. This is a non-renewable lifetime maximum and counts toward the lifetime dollar maximum of \$7,500 as well.

If the enrollee or their responsible party elects to institute curative treatment or extraordinary measures to sustain life, the enrollee will not be eligible to receive further hospice care benefits.

Hospice Care for Personal Choice Members

Respite care of a maximum of seven days every six months is covered at 100 percent In-Network. Out-of-Network services are covered at 70 percent of the UCR (usual, reasonable and customary) Charge. Precertification is required for all In-Network and Out-of-Network Hospice care. Failure to precertify Out-of-Network services may result in a 20 percent reduction in benefits payable for Hospice Care services.

Enrollees are eligible for Hospice Services when their attending physician certifies that they have a terminal illness with a medical prognosis of six months, or less and when the enrollee elects to receive care primarily in their home to relieve pain and to enable them to remain at home rather than to receive other types of care.

Enrollees are also eligible for short-term inpatient care in a Medicare-certified Skilled Nursing Facility when the Hospice considers such care necessary to relieve primary caregivers in your home. Up to seven days of such care every six months will be covered.

Hospice benefits are subject to Personal Choice Program precertification.

No Hospice Care benefits will be provided for:

- Services and supplies for which there is no charge
- Research studies directed to life lengthening methods of treatment
- Services or expenses incurred in regard to the patient's personal, legal and financial affairs (such as preparation and execution of a will or other dispositions of personal and real property)
- Care provided by family members, relatives and friends
- Private duty nursing

Hospice claims under the PEBTF in 2003-2004 totaled \$307,371.

G. Why Our Picture of Pennsylvania is Incomplete

Despite the wealth of quantitative and descriptive data in the preceding sections, there is much that we still do not know about Pennsylvanians' experience of end-of-life care. The effort to assemble the information that we do have reveals that a significant barrier to making improvements to our system of care is the lack of easily accessible, centralized data on many of the significant indicators of the system's performance. *Improved data collection and research*

targeting statewide end-of-life practices and resources should be among the most urgent items on the state's agenda for reform.

Although numbers, causes, and locations of death are routinely gathered by government, as are basic demographic characteristics such as age and race, information on dying pathways—that is, the trajectories of illness and patterns of utilization of various levels of care—requires more specialized studies than have been undertaken to date. Moreover, in the absence of integrated, comprehensive computer based patient records, such studies will generally be small scale and limited to a few institutions or communities. This will limit their generalizability. The types of data not currently being collected statewide, but, if it were, would help track current practices and improvements over time, might include:

- Current percentage of Pennsylvania hospitals with palliative care programs
- The timing of documentation of Advance Directives (e.g. DNR, living will, health care power of attorney) in patient charts in hospitals and nursing homes
- Breakdown of medical treatments (i.e. ventilators, resuscitation, surgery) provided, or withdrawn during a patient's final hospital stay
- Administer a "quality of death" question to a random sample of survivors of Pennsylvania decedents via a follow-back survey (using vital statistics records as the sampling frame. An example of a validated question could be pulled from "national quality of death surveys or from other measures established in collaboration with state agencies.)

IV. State and Regional Models of Reform

Faced with the deficiencies in end-of-life care documented above, a number of states have established broad-based coalitions to implement reforms. A sampling of state and regional initiatives from around the country indicates several possible approaches that could serve as models for Pennsylvania.

A. State Initiatives

1. West Virginia

The West Virginia Center for End-of-Life Care is based at the West Virginia University Center for Health Ethics and Law. It consists of collaborating organizations from State Government (e.g., the Bureau of Senior Services, Department of Health and Human Resources, Guardianship Commission, Boards of Medicine, Pharmacy, and Osteopathy, the West Virginia Health Care Authority) and statewide organizations (e.g., the state Medical Association, Bar Association, Hospice Council, Hospital Association, Cancer Pain Initiative, Nurses Association, Heart Association, Diabetes Association, and many other professional societies and disease-related advocacy groups).

The Center's principal mission is to provide coordination, education, and resources to the citizens of West Virginia in the areas of pain management and assuring respect for an

individual's wishes for care and decision making near the end of life. The major activities of the Center include:

- A statewide needs assessment
- Educational programs
- Resources for patients and families

It maintains a website (www.hsc.wvu.edu/chel/wvi) and sponsors educational programs for health professionals and the general public at locations across the state. Among the resources that the Center has developed and disseminated is the POST (Physician's Orders for Scope of Treatment), which is designed to assure continuity of patient-centered decision making across all sites of care. To support the acceptance and widespread utilization of the POST form, the Center's website contains a statement of policy favoring the use of the POST, relevant enabling legislation, the form itself, FAQs, and a PowerPoint presentation for professionals to use in discussing the POST with patients and families.

Additional web-based resources include Advance Care Planning documents, relevant state laws, informational videos, an online directory of end-of-life resources arranged by county, and pain management tools such as pain assessment instruments and patient information.

2. Oregon

The Task Force to Improve the Care of Terminally-Ill Oregonians is based at the Center for Ethics in Health Care of the Oregon Health and Science University. Its organizational membership mirrors West Virginia's, spanning the range of statewide health professional organizations, health systems, the bar association, and government agencies. The Task Force's main goals are to:

- Share information about end-of-life choices and options for care
- Increase awareness and respect for diverse values and viewpoints
- Develop professional standards for end-of-life care in general and, in particular, regarding implementation of the Death with Dignity Act (Oregon's physician-assisted suicide law)
- Disseminate educational resources for health professionals and the public
- Foster relationships and networking

The Task Force website (www.ohsu.edu/ethics) includes a county-by-county end-of-life resource directory, forms and information related to the POLST (Physicians Orders for Life-Sustaining Treatment), which has the same purpose as the POST form in West Virginia, and information from the Oregon Department of Human Services regarding the physician-assisted suicide law.

The Task Force has also conducted statewide research and needs assessment, resulting in its own "Oregon Report Card," based on statewide data related to end-of-life care and utilization of resources. The website also contains links to the Washington, DC-based Center to Improve the Care of the Dying's Toolkit of Instruments to Measure End of Life.

3. Michigan

Michigan's Commission on End-of-Life Care was appointed by the Governor in June, 1999. Its mandate was to provide a set of recommendations "on how Michigan may improve the humane and dignified treatment for Michigan citizens at the end of life." After public hearings, consultations with experts, and review of policies related to end-of-life care, the Commission issued its 170-page report on August 30, 2001. The report presents a detailed statistical portrait of the demographic, clinical, legal, and organizational aspects of end-of-life care in Michigan. This is followed by the Commission's detailed reports and recommendations related to:

- professional education
- pain and symptom management
- reimbursement
- long-term care
- decision making for end-of-life
- family issues
- public and professional opinion
- barriers to effective care

The Commission Report is available on the website of the Michigan Department of Community Health, www.michigan.gov/mdch (click on Physical Health and Prevention, choose Services for Seniors, then End of Life). The site also contains links to an Information Resource Guide on End-of-Life Care, Michigan's Dignified Death Act and its Do-Not-Resuscitate Procedure Act, and information about hospice care in Michigan. Finally, "Completing a Life: A Resource for Taking Charge, Finding Comfort, and Reaching Closure," is an interactive website, also available as a CD-ROM, produced by Michigan State University to allow patients and families "to learn about the practical, emotional, spiritual and medical issues faced by those with advanced illness." (www.commtechlab.msu.edu/sites/completingalife/)

B. Regional Initiatives

1. Missoula, Montana

The Missoula Demonstration Project, now known as the Life's End Institute, was established in 1996. Its initial purpose was to conduct research on the experience of dying people in this small western city. The research highlighted the importance of broad-based networks of support for dying patients and families. The Missoula Project responded to this need by developing community engagement activities, educational initiatives for health care providers, patients, and families, and special outreach efforts to the faith communities in the Missoula area.

The Missoula Project created task forces on advance care planning, life stories, faith communities, pain, and end-of-life education in the schools. The Project website (www.lifes-end.org) provides advanced care planning materials, as well as information about ongoing programs and an inventory of research instruments and tools for other communities to use for their own needs assessments. The Life's End Institute also offers expert consultation on a range of community-based end-of-life initiatives.

2. LaCrosse, Wisconsin

The “Respecting Choices” Program in LaCrosse, Wisconsin, based at the Gunderson Lutheran Medical Center, originated in 1991 as a collaboration among the city’s major health organizations. Its purpose was to develop an improved model of end-of-life planning and decision making that would combine print and electronic media with personal assistance by trained staff. From this beginning, “Respecting Choices” grew to encompass four major goals:

- To ensure systems of care match patient preferences
- To improve end-of-life decision making
- To reduce over- and under-treatment of patients near the end of life
- To reduce family caregiver burden

To accomplish these goals, the program utilized methods of community engagement, professional education, development of standards of practice, and organizational change. Curricula, training manuals, and supplementary materials about end-of-life care and advance planning were developed for several audiences:

- Facilitators, who can work with groups wishing to improve end-of-life care using the “Respecting Choices” model
- Organizations and communities
- Special populations
- Hospital Ethics Committees

“Respecting Choices”—as an integrated, community-based intervention to improve end-of-life planning—has been implemented in over 30 communities nationwide, and the program’s staff are available for consultation. The program website, which includes an Advance Care Planning QI Toolkit, is at www.gundluth.org/web/ptcare/eolprograms.nsf.

3. Pittsburgh, Pennsylvania

In July, 2004, community leaders in Pittsburgh established the Coalition for Quality at the End of Life (CQEL). CQEL is made up of approximately 40 organizations, representing health system leaders, provider organizations, insurance companies, citizen groups, governmental agencies, philanthropic organizations, clergy, and others who are concerned about the quality of care that is available to critically ill and dying people and their families in Western Pennsylvania.

CQEL’s mission is to improve end-of-life care in the region by identifying and collaborating with the key stakeholder groups. CQEL pursues its mission by engaging the community to build demand for better end-of-life care, building capacity among local health care institutions for the delivery of skilled and compassionate care, focusing attention on the regulatory and financial barriers to quality end-of-life care, and by promulgating appropriate standards and measures.

A CQEL subgroup has been established for each of the four domains, and each group is charged with developing specific action plans in its area of responsibility. Examples of subgroup initiatives currently in the planning or implementation phases are:

- An online survey of health providers, designed to identify perceived barriers (regulatory, financial, or institutional) to providing effective end-of-life care
- Focus groups with members of various segments of the region’s population, including, for example, members of minority communities, the elderly, people with disabilities, parents of seriously ill children, young adults
- Public, professional and legislative educational initiatives aimed at encouraging the adoption of the POLST (Physician Orders for Life-Sustaining Treatment)
- Developing a set of relevant measures that could be endorsed and promulgated by CQEL as benchmarks of progress toward improved end-of-life care

V. Conclusion

In Pennsylvania, like the rest of the nation, most people die from chronic diseases after living for many years with varying levels of discomfort, disability, and dependent on others. In Pennsylvania, like the rest of the nation, systems of care and support have not kept up with these patterns. Specific subgroups within the population, such as children, people with mental and physical disabilities, incarcerated individuals, racial and ethnic minorities, and the elderly, often pose unique challenges to systems of care. Although the majority of people want to die at home, people in Pennsylvania tend to die in hospitals, nursing homes and personal care homes. Pennsylvania is under-supplied with trained, certified providers of specialized end-of-life care.

Based on the grades Pennsylvania received in the Means to a Better End Report, there is room for improvement. As noted above, however, the categories evaluated in the Means Report are only a starting point. Additional areas of concern emerged in the preparation of this background paper. The following table combines the two perspectives to delineate the scope of Pennsylvania’s agenda for end-of-life reform.

Table 10.
Targets for Improvement in End-of-Life Care in Pennsylvania

From “Means to a Better End”	From the Background Paper
<ul style="list-style-type: none"> • Advance directives • Location of death • Hospice use • End-of-life services in hospitals • ICU utilization near end of life • Pain in nursing home residents • State pain policies • Certified providers 	<ul style="list-style-type: none"> • Collection of relevant data • Management of pain • Recognition and management of depression • Coordination among systems of care • Reimbursement • Community and provider awareness of end-of-life services

The topics listed in Table 10 should provide useful guidance to the state’s Task Force for Quality at the End of Life at the symposium in June, 2005, and in subsequent recommendations to the Governor. It is worth noting in conclusion, however, that achieving the goal of a dignified, comfortable, and personally meaningful death for all Pennsylvanians is not the responsibility of

state government alone. The state is only one actor—albeit a very significant one—in the universal human process of coming to terms with life’s ending. Families, faith communities, neighborhoods, civic groups, employers, professional caregivers, and many others have the opportunity and responsibility to help people die in ways that affirm the values and qualities that make life itself worthwhile. This background paper has attempted to provide information that will enable state government, through laws, policies, regulations, and budgets, to make the efforts of all of these people easier rather than harder.

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