



IMPROVING END-OF-LIFE EXPERIENCES FOR PENNSYLVANIANS

Task Force for Quality at the End of Life

Report and Recommendations to Governor Edward G. Rendell

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EXECUTIVE SUMMARY

WE APPLAUD GOVERNOR RENDELL FOR HIS LEADERSHIP IN CREATING THE TASK FORCE

for Quality at the End of Life and for allocating resources to facilitate this effort. Without his support, this report would never have come about. This report is the work of that Task Force, and these are its primary goals:

- To create momentum for change in policy, systems, and grassroots community activity to reform and improve palliative and end-of-life care;
- To mobilize stakeholders in the public and private sectors for action by providing them with information and pathways toward reform of palliative and end-of-life services and care;
- To energize local citizen action groups throughout the state to organize and create change around palliative and end-of-life care.

In sharp contrast to 1900, when acute infections constituted the leading causes of death, today most people die from chronic progressive illnesses. The cumulative effects of these illnesses on individuals and their families present an increasingly urgent challenge for our health care delivery system, particularly in Pennsylvania, where 15% of the population is 65 or older, as opposed to 12% nationally. Other groups, such as children, people with disabilities, people living in rural areas, state prisoners, and the 17% of Pennsylvanians who are members of minority groups, all require action by providers and policy makers to address issues associated with serious illness and the need for improved palliative and end-of-life care.

A recent report commissioned by the Robert Wood Johnson Foundation, evaluated each of the 50 states on a number of parameters related to the provision of end-of-life care. Most states earned poor grades on the majority of the elements; Pennsylvania's average grade was a D.

In addition to the goals mentioned above, our state's reform of palliative and end-of-life care issues must address the following areas of concern:

ADVANCE DIRECTIVES

Pennsylvania requires improved, more supportive policies governing advance directives and greater awareness of the advance care planning process through education of health care professionals and the broader community. In addition, Pennsylvania should adopt a system to assure continuity of care and respect for patient preferences across care settings.

PROVISION OF PALLIATIVE CARE

If we are to ensure the optimal provision of care for seriously ill and dying individuals, then improved standards for palliative care, better coordination of care, and more highly trained personnel in health care facilities are key elements. This is especially relevant for acute care hospitals and skilled nursing facilities where, currently, the majority of Pennsylvanians die.

FINANCING CARE

Medicare currently spends 27% of its total dollars on people who are in their last year of life. About 70% of people who die each year are covered by Medicare, with about 13% also covered by Medicaid. Advances in technology and modern medicine have led to an increase in life expectancy and in the number of persons living with chronic illnesses. The effect of these increases not only places a greater burden on acute care and long-term care funding, it also fails to direct resources where they are needed. State policy makers, health care systems, commercial health insurers, employers, and consumer advocacy groups need to promote public awareness of palliative care and work together to design new health care delivery and financial structures that establish an optimal balance between quality palliative and acute care.

SPECIAL POPULATIONS

Attitudes, values, and needs for care near the end of life vary among individuals and groups. Populations with particular concerns include older adults, children, racial-ethnic minorities, people with disabilities, rural populations, and prison populations. Moreover, some Pennsylvanians believe that the manner in which end-of-life decisions are made, applied, or delivered can have a different and potentially harmful impact on them in the absence of appropriate safeguards.

PROFESSIONAL EDUCATION

The shortcomings in professional palliative and end-of-life education have been thoroughly documented. Pennsylvania's health care community requires a more comprehensive palliative and end-of-life curriculum. Educational reform is needed and must be implemented by all of the various institutions and groups charged with maintaining the content and quality of health professions education.

RAISING AWARENESS IN THE COMMUNITY

There are several key topics that are crucial to improving the public's understanding of palliative care and the end-of-life experience. They are: communication about death and dying in the context of significant personal relationships; recognition of and support for the lay caregiving experience; and accurate information about hospice and palliative care, and about pain and symptom management.

RESEARCH, MEASUREMENT, AND DATA

As its elderly population continues to grow, Pennsylvania urgently requires improved systems for research, analysis, measurement, and consistent tracking of efforts in palliative and end-of-life care. Both governmental departments and non-governmental organizations should be encouraged to share in these tasks.

IN CONCLUSION

Providing quality end-of-life experiences for all Pennsylvanians is a challenge of increasing urgency, and one that must be tackled by all of us. By working together as legislators, government officials, medical professionals, educators, activists, and citizens, we can address these most basic conditions of human life with the intelligence, compassion, and resources they deserve.

IN JANUARY 2005, GOVERNOR RENDELL

appointed a statewide Task Force for Quality at the End of Life, under the leadership of Secretary of Aging, Nora Dowd Eisenhower. The Task Force's charge was to recommend improvements in our state's capacity to maintain the quality of life of its growing population of elderly and those with serious illness, as well as to improve Pennsylvania's performance on a number of benchmarks for quality end-of-life care. The Task Force is comprised of representatives from academia, government, medical institutions, consumers, providers, and disability, faith-based, and minority communities. This report is the work of that Task Force. Additional details of the Task Force's work, including further data on end-of-life care in Pennsylvania, demographic information, and complete documentation, can be found in two other Task Force documents, "End-of-Life Care in Pennsylvania: A Background Paper," and "Final Report and Recommendations of the Task Force for Quality at the End of Life." Both are available online at www.aging.state.pa.us

BACKGROUND

Biomedical science and public health have combined with rising living standards to produce spectacular gains in health and longevity in our society. For the most part, however, these advances have left untouched a large reservoir of unrecognized suffering, namely, the burdens of physical disability, dependency, and social isolation that accompany a host of chronic, progressive illnesses when they reach their advanced stages. In spite of our most promising medical advances, people ultimately age, weaken, and die. The cumulative effects of chronic serious illness on individuals and their families constitute a frontier for our health care delivery system that calls urgently for our exploration. This is particularly true in Pennsylvania, whose large population of older adults is most susceptible to these effects.

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 years, and most deaths were attributed to acute infectious causes. Few people lived with chronic progressive illnesses and worsening disabilities. Advances in medical science in the past century have transformed this trend completely. In the United States today, the average life expectancy at birth is estimated at over 77 years, and most deaths are due to chronic progressive illnesses such as heart disease and cancer. Because considerable

medical technology now exists that can postpone death, the associated costs of end-of-life care have escalated, and most people die in hospitals or nursing homes, attended to by strangers. For patients who try to cope with these conditions at home, the financial, physical, and emotional burdens of caregiving fall heavily on isolated nuclear families and predominantly on women.

The current health care system evolved to provide care for acute illnesses, but it is poorly prepared to provide comprehensive, coordinated care for those with a serious chronic illness or at the end of life. To maintain their best possible health-related quality of life for as long as possible, seriously ill Pennsylvanians require proactive efforts to achieve a better balance between acute, cure-oriented approaches and supportive palliative care.

Recently, Last Acts, a program of the Robert Wood Johnson Foundation, commissioned a report, *Means to a Better End: A Report on Dying in America Today*, that evaluated each of the 50 states on a number of parameters related to the provision of high-quality end-of-life care. Most states earned poor grades on the majority of the elements; PENNSYLVANIA'S AVERAGE GRADE WAS A D. The following were among the key findings supporting Pennsylvania's low grades:

- Hospice use is low (only 21% of PA residents over the age of 65 who died 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.
- Not nearly enough Pennsylvania hospitals have palliative care programs to care for seriously ill and dying patients.
- The state is severely lacking in palliative care-certified physicians and nurses.

Pennsylvania’s challenge is more than poor grades on a report card. These poor grades translate into real suffering for individuals and families. People with serious, advanced disease fear pain and other physical symptoms. Unfortunately, pain is often managed poorly, despite the ready availability of safe and effective treatments. Minority populations are particularly affected.

For family caregivers, the physical, emotional, financial, and social impact of providing care for a relative with a serious chronic illness is aggravated by restrictions on personal time, disturbance of routines, and diminished time for self-care. One family caregiver, whose husband survived an automobile accident with severe, permanent disabilities, described her experience as follows:

“I feel abandoned by a health care system that commits resources and rewards to rescuing the injured and ill but then consigns such patients and their families to the black hole of chronic ‘custodial care.’ Family caregivers must be supported, because the health care system cannot exist without them... Exhausted caregivers become care recipients, leading to a further, often preventable, drain on resources. Does my managed-care company realize,

“Hello? Is anyone listening?”

*for instance, that during the past year it paid more for my stress-related medical problems than for my husband’s medical care?... Hello? Is anyone listening?”*¹

Currently, people age 65 and older comprise 15% of Pennsylvania’s total population (compared to 12% in the U.S.). This number is only expected to grow. It is estimated that one in five U.S. citizens will be over the age of 65 by 2030. Of this group, the oldest (age 85 and over) are projected to double

to 7 million by 2020. In accordance with U.S. Census Bureau projections, Pennsylvania is expected to rank fifth in the proportion of older adults among all the states in 2025.

Also, Pennsylvania is a culturally diverse state. Non-white racial and ethnic groups comprise about 17% of Pennsylvania’s population, the largest groups being African American (10%) and Hispanic (4%). In 2004, minorities accounted for about 10% of all deaths in Pennsylvania. Other groups, including children, people with disabilities, people living in rural areas, and state prisoners need particular attention around ensuring access to optimal end-of-life care.

Improving care for those with a serious chronic illness and at the end of life is in the interest of all Pennsylvanians. As the Task Force concluded in its preliminary background paper on the state of end-of-life care in Pennsylvania,

“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.”

-Task Force Background Paper



¹ Levine, C. The Loneliness of the Long-term Caregiver. *New England Journal of Medicine*, 1999 340: 1587-1590.

This report addresses the experiences and needs of people with serious or advanced illnesses that have a significant impact on their quality of life, and the experiences and needs of those who care for them. This group of people is variously described as “seriously ill,” “terminally ill,” with “life-threatening” or “life-limiting” illness, and similar terms. The care they require may be described as “supportive care,” “comfort care,” “hospice care,” “palliative care,” “end-of-life care,” and so on. For many people, the association of words such as “hospice” or “palliative care” with death, or the very last stage of life, is a barrier to open discussion about their needs, values, or preferences for medical care in the face of serious illness. In reality, however, palliative care can be provided at the same time as life-prolonging and disease-modifying therapies. No specific therapy is excluded from consideration. An important goal of palliative care is to facilitate communication between the health care team, patient, and family to make sure that medical treatments reflect the patient’s values, quality-of-life preferences, and goals, and take into account family needs, beliefs, and culture.

Accordingly, this report is for everyone who is or may be concerned about maintaining their values, sense of dignity, and quality of life to the greatest possible extent, regardless of the challenges they face from a serious medical condition. The services and support systems that fall within the labels “hospice” or “palliative care” have as their supreme focus a simple message to every seriously ill person (and caregiver); in the words of Cicely Saunders, the founder of the modern hospice movement, “*You matter because you are you, and you matter until the end of your life.*”

ADVANCE CARE PLANNING AND POLICIES

Since the Task Force wrote this chapter assessing the limitations of Pennsylvania advance directive law, new legislation in the form of PA Act 169 has been passed. Therefore, the following now serves as a frame of reference for assessing this legislation.

Advance care planning is the process by which patients prepare for possible future incapacity, either by indicating in advance their preferences for medical care or by designating a surrogate decision maker who is authorized to speak on their behalf. The main purpose of advance care planning policies and the documents that are known as *advance directives*, *living wills*, *health care proxy*, or *power of attorney*, is to bring patients, who are unable to participate

in joint health care decision making, as close as possible to their ideal end-of-life preferences.

Nationally, only 20 to 30% of adults have completed advance directives, and even then, evidence suggests that advance directives do not always influence decision making. Common difficulties include the following:

- Documents cannot be located when needed.
- Documents are too vague for a patient’s actual circumstances.
- The patient’s preferences are ignored in favor of what physicians or family members believe fits the patient’s immediate interests.

In response, improved communication of wishes for care in Pennsylvania must encompass the following broad areas:

- Community awareness and education about the advance planning process.
- Education of health care professionals.
- Improvements to Pennsylvania’s current advance directive legislation.
- Adoption of a statewide system to assure continuity of care and respect for patient preferences across the entire health care system.

Under current Pennsylvania law, the only mechanism to communicate patients’ wishes when they cannot speak for themselves is an advance directive. However, the current advance directive law suffers from the following limitations:

A. THE DEFINITION OF TERMINAL ILLNESS IS TOO STRICT.

Under current law, an advance directive becomes operative only when the patient has been diagnosed as permanently unconsciousness or terminally ill. Although consensus was not achieved on this point, some Task Force members believe that these criteria are too strict, with the result that the wishes of people with advance directives are not followed because their condition is judged to fall outside those narrow parameters.

B. WHEN THERE IS NO ADVANCE DIRECTIVE, THE SURROGATE’S AUTHORITY IS AMBIGUOUS.

The current Pennsylvania advance directive law is silent on the topic of decisions for patients who have not formally designated a surrogate decision maker, especially when their condition falls outside the narrow definitions of “terminally ill.” Physician practice varies across the state in recognizing the authority

of surrogate decision makers in these circumstances. The present legal environment allows physicians the flexibility to assess the reliability of potential surrogate decision makers and to proceed in trying to ascertain the patient's wishes.

Close family and friends almost always can be trusted to protect the interests of the patient without the need for judicial oversight or intervention. They are usually the most knowledgeable about the patient's preferences, goals, and values; they have an understanding of the nuances of the patient's personality and have a special bond with the patient. This point of view, however, is not universally shared, as noted below in Section D.

C. ADVANCE DIRECTIVES AND DO-NOT-RESUSCITATE ORDERS ARE LIMITED IN PORTABILITY.

Patients' care wishes are documented on their chart in a particular health care institution. When patients are moved to another setting, determining their wishes en route or before advance care discussions are repeated and documented in the new setting can be hit or miss. In addition, code status orders do not transfer from facility to facility. For example, an order in a skilled nursing facility that a patient is not to be placed on life support is not in effect if the patient is transferred to an emergency room or acute care hospital. The steps required to establish new code status orders often do not come together before decisions about life support must be made in the rapid-fire environment of emergency rooms or intensive care units. This often results in patients receiving unwanted and unplanned life support measures, including cardiopulmonary resuscitation.

Currently, the only way to have an effective "Do-Not-Resuscitate (DNR)" status outside of an institution in Pennsylvania is through the use of the out-of-hospital DNR order. While this option has been available in Pennsylvania for two years, to date it has not reached any measurable level of use by the public. Barriers to wider use include: the patient must be declared terminally ill or permanently unconscious, and then a physician must provide the appropriate identification method for the patient. Similarly, patients who do not wish to be resuscitated but do not yet meet the legal definition of terminally ill cannot avail themselves of the system.

D. MEMBERS OF THE DISABILITIES AND MINORITY COMMUNITIES HAVE DEEP CONCERNS REGARDING ADVANCE DIRECTIVES AND DNR ORDERS.

Minority communities and persons with disabilities, in particular, have expressed deep concerns regarding the appointment of surrogate decision makers for people who do not have advance directives. Advocates for minority groups cite distrust of the medical community as a major source of concern. For persons with disabilities, concerns are rooted in the prevalence of stereotypes of persons with disabilities and fear that ill-informed assumptions about the quality of life that can be enjoyed while dependent on life-sustaining technology will prompt surrogates to withhold or withdraw life support from persons with disabilities or other vulnerable groups inappropriately or unjustly. Lack of clarity and consistency in current interpretation of DNR orders is also a factor underlying the disability community's concerns. Pennsylvania's continuing dialogue around advance directive policy should include a wide spectrum of voices from the minority and disabilities communities.

Recommendations for Better Advance Care Planning

1. Updating advance directive law could assist tremendously in empowering surrogates, assigning default surrogates, broadening the legal definitions surrounding terminal illness, standardizing and simplifying advance directive procedures and forms, and mandating the development of a statewide, Health Insurance Portability and Accountability Act (HIPAA)-compliant registry for advance directives.
2. Task force members believe that to augment the transferability of advance directives, the state should adopt a portable form like the Physician Orders for Life-Sustaining Treatment (POLST) paradigm (www.polst.org). Developed specifically for patients with a serious illness and advanced frailty, the centerpiece of the program is the POLST document. The POLST document is a brightly colored medical order form that converts patient treatment preferences into written medical orders based on conversations with health care professionals, the patient, and/or surrogates about treatment goals. The form accompanies patients across health care settings to ensure that their wishes are honored throughout the health care system. As of this writing, at least 13 states have adopted versions of the POLST program, which reflects a high degree of acceptance by health care professionals.
3. In addition to the above measures, medical insurance coverage should provide incentives to physicians and patients to have the extended conversations that are required for advance care planning.

PALLIATIVE CARE

Palliative care is patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. It addresses physical, intellectual, emotional, social, and spiritual needs while facilitating patient autonomy, access to information, and choice of care. This type of comprehensive assessment and management of symptoms is essential to ensuring comfort and quality of life for seriously ill patients and their families.

Palliative care is provided in many settings and forms.

Hospice care is a vehicle that provides palliative care to patients at home, in nursing homes, or in specialized in-patient facilities. Under current federal regulations governing hospice reimbursement, to qualify for hospice care, patients typically must have a life expectancy of six months or less and agree to forgo curative treatments.

Regardless of setting, palliative care is particularly effective in alleviating symptoms associated with advanced illness. Pain is one of the most common and widely feared symptoms in patients near the end of life and is frequently under-assessed and poorly managed. Populations with an increased risk of underassessment include older adults, children, and cognitively impaired and unconscious patients. Unrelieved pain and other physical symptoms can also prompt or heighten psychosocial and spiritual distress and suffering and have been linked with increased patient desire for hastening death.

The reasons for poor pain and symptom management are multifactorial, but some of the primary contributing factors include lack of appropriate education among physicians, patients, and their families; fragmented or nonexistent systems for symptom assessment and management; lack of standardization and audits of institutional pain and symptom management practices; and the fact that, historically, pain management has been a low priority for the medical community.

Recommendations for Improving Palliative Care

1. The Pennsylvania Medical Society and Pennsylvania State Nurses Association, in collaboration with the Pennsylvania Hospice Network, should create a web-based statewide clearing-house for palliative care, including standardized best practices, information, and resources.
2. Pennsylvania state government should require evidence of baseline education in palliative care tied to professional state licensure;

increase funding for scholarships; offer incentives for advanced training or certification in palliative care, such as End-of-Life Nursing Education Consortium (ELNEC), Education on Palliative Care and End-of-Life Care (EPEC) programs, or board certification; and adopt the Federation of State Medical Board's *Model Guidelines for the Use of Controlled Substances for the Treatment of Pain*.

COORDINATION OF CARE

Care for people who are in the last phase of life is often delivered in a variety of settings, including acute care hospitals, skilled nursing facilities, personal care facilities, inpatient hospice units, and at home with either home health care or hospice care. Because of physician specialization and the current model of reimbursement, when patients move between care settings, it is unlikely that care will be rendered by professionals who know the patients and are familiar with their medical and social history.

Other key elements that adversely impact coordination of care across settings include a lack of communication between physicians and caregivers when patients transition from one setting to another. In many instances, caregivers are unfamiliar with available resources in the new setting, and professionals may fail to make appropriate referrals.

Recommendations for Improving Coordination of Care

1. Pennsylvania should encourage standardization of medical record keeping and information transmission that can be accessed by multiple providers, and work with accrediting bodies such as the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) and the Community Health Accreditation Program (CHAP) to mandate initiatives such as the POLST.

PALLIATIVE CARE SPECIALISTS IN HEALTH CARE FACILITIES

State-of-the-art palliative care requires an interdisciplinary team, composed at a minimum of physicians, nurses, nursing assistants, social workers, and chaplains. Currently, there are only 25 palliative care teams in Pennsylvania providing consultation and services in health care facilities, largely hospitals. Patients under the care of these teams may still receive treatments directed at curing or modifying their underlying life-threatening illnesses. This differs from hospice care, where regulations and reimbursement streams limit the continued use of curative or life-prolonging treatment.

Implementation of palliative care services has been highly successful in achieving the following:

- Reduced symptom burden
- Improved patient/family/staff satisfaction
- More appropriate alignment of goals of care
- Improved resource allocation through avoidance of unwanted or non-beneficial care

Nursing facilities are even less likely than hospitals to have a palliative care team. Furthermore, the ability of nursing facilities to provide palliative care is hampered by a regulatory environment that is prejudiced toward life-sustaining and prolonging treatments over patient comfort in the context of natural decline. Lack of staff and lack of training also impede a nursing homes' ability to provide palliative care and often, even in the best facilities, nursing aides, who provide most of the care, are paid very little.

Recommendations for Increasing Palliative Care Specialists in Health Care Facilities

1. The state should create incentives for broader creation and utilization of palliative care teams that include public reporting of hospitals and nursing facilities offering these services.
2. Further studies are needed to test the hypothesis that increased patient-to-staff ratios in long-term living facilities improve care and outcomes for residents who are at the end of life.
3. Pennsylvania needs to revise regulatory guidelines for long-term living facilities by requiring that palliative care principles and practices are included in domains of licensure of nursing facilities.
4. Incentives should be created to expand the number of trained personnel in these institutions.
5. One option for nursing facilities to improve end-of-life care in their facilities is to contract with hospice programs.
6. Another option is paying nursing aides a living wage.

STANDARDS FOR PALLIATIVE CARE

New national initiatives have recently been put in place to standardize the practices of palliative care. These include *The National Consensus Project for Quality Palliative Care* (NCP) and the National Quality Forum's (NQF) *Framework and Preferred Practices for a Palliative and Hospice Care Quality Project*.

In 2004, the NCP released its *Clinical Practice Guidelines for Quality Palliative Care*, which describes the domains essential in addressing patient needs through comprehensive palliative care:

- Structure and Processes of Care
- Physical Aspects of Care
- Psychological and Psychiatric Aspects of Care
- Social Aspects of Care
- Spiritual, Religious, and Existential Aspects of Care
- Cultural Aspects of Care
- Care of the Imminently Dying Patient
- Ethical and Legal Aspects of Care

The NQF is a broad-based, nonprofit organization with the mission of improving the quality of American health care. The NQF recently produced a document titled, *A National Framework for Palliative and Hospice Care Quality Measurement and Reporting*. This document embodies a theoretical framework on which more quantitative quality indicators may be formulated.

These and other informational documents can be downloaded from the NCP's website at:

<http://www.nationalconsensusproject.org>.

Information about NQF's *Framework* document is available at: <http://www.qualityforum.org>.

Recommendations for Implementing Palliative Care Standards

1. A single state agency should oversee that all health care providers and local governments follow the national standards set forth in both of the aforementioned documents. This agency should be responsible for finding creative incentives to encourage and support the standards, providing education and outreach for these standards, and leveraging the weight and authority of the Commonwealth's authority to make the case for their adoption.

FINANCING CARE FOR THE LAST PHASE OF LIFE

In Pennsylvania, as in most states, financing for health care is not the sole responsibility of one public and private funder. Many different funding streams, such as Medicare and Medicaid, are modeled after each other, and it should come as no surprise that problems in one program exist in others. Also, private insurance plans vary tremendously throughout the state and many community-based organizations, which are “on the ground” providing direct services to people, vary as well. Given the convergence of these programs, recommendations for reform must address all elements of reimbursement and care needs, with emphasis on the largest payors, Medicare and Medicaid. Estimates for the past 20 years show that Medicare has spent 27% of its total costs on people who are in their last year of life and on average, about 70% of people who die each year are covered by Medicare, with 13% covered by Medicaid.

Barriers within the current structures and mechanisms by which we pay for care for seriously ill Pennsylvanians stand in the way of utilizing our finite health resources in the most efficient and effective ways to optimize quality, value, and responsiveness to the needs of these individuals and their families. Misaligned incentives in reimbursement influence patterns of care and often result in lower quality or inappropriate care. Currently, there is no formal recognition of palliative care as a medical specialty or of palliative care units within hospitals or long-term care facilities. Palliative care programs are reimbursed less than other medical specialties since physicians and other health care providers cannot bill for the full spectrum of palliative care services they provide. One example of a non-reimbursable activity is time spent counseling patients and families regarding advance care planning.

Given the lack of a defined palliative care insurance benefit, health care services for people who are seriously ill and near the end of life are provided in diverse settings with a variety of provider types and ways to finance them. This patchwork of financing and provision of services allows gaps, which often leave patients’ needs unmet. One way to potentially fill these systemic gaps could be to provide Pennsylvanians access to palliative care services as part of their insurance network, including those in the Medicaid program, and to align financial incentives of providers of these services with the types of care that people at the end of life need and want.

HOSPICE CARE

Since its inception, hospice care has remained the only clearly defined benefit for people who are at the end of life. Most Pennsylvanians with health insurance have a hospice benefit and access to one of the state’s 139 Medicare-certified hospice programs. There are rare exceptions such as self-funded groups that choose not to cover hospice and Special Care Plans for those with low incomes.

To elect the hospice benefit, an individual must be certified by two physicians who believe that, *to the best of their medical knowledge, the disease, if it runs its normal course, limits the patient’s prognosis to six months or less*. Given that most Americans die from long-term chronic diseases that have unpredictable courses, the variability of the terms *medical knowledge* and *normal course*, and the requirement that physicians differentiate between a four-, six-, or eight-month prognosis have led many experts to call for the elimination of these restrictions for hospice.

Additionally, late stage referrals continue to challenge the hospice industry, which is financed on a fixed per diem basis. Short lengths of stay, sometimes referred to as *brink of death care*, do not provide patients and families the opportunity to benefit from the resources and expertise that a hospice team has to offer. They also do not allow the hospice provider to maintain financial viability by spreading out the costs per day, since in most cases hospice incurs the greatest costs on the first and last days of a patient’s enrollment period. In 2000, 30% of hospice patients died within one week of enrolling compared to 21% in 1992.

ACUTE CARE

Supported by medical education and finance policy, the most common response to critical illness by the medical community is to try to stave off death with sophisticated technology, procedures, and medications. The Dartmouth Atlas of Health Care, a project that works to accurately describe how medical resources are distributed and used in the United States, recently published the following data for Medicare patients who died in hospitals between 1999 and 2003. This data shows that Pennsylvania’s rates of Intensive Care Unit/Coronary Care Unit (ICU/CCU) use were higher than the national average for Medicare decedents in the last six months of life and during hospitalization in which the death occurred.

**PERCENT OF DECEDENTS ADMITTED TO ICU/CCU
DURING THE HOSPITALIZATION IN WHICH DEATH OCCURED
STATE LEVEL RATES 2003**

AREA	POPULATION	RATES	RATIO TO BENCHMARK	SURPLUS/DEFICIT
*Pennsylvania	77,972	17.82	-	-
National Average	1,501,940	17.75	1	-1,088

**PERCENT OF MEDICARE DECEDENTS ADMITTED TO ICU/CCU
AT LEAST ONCE DURING THE LAST SIX MONTHS OF LIFE
STATE LEVEL RATES 2003**

AREA	POPULATION	RATES	RATIO TO BENCHMARK	SURPLUS/DEFICIT
*Pennsylvania	77,972	39.87	-	-
National Average	1,501,940	37.36	0.94	-37,731

Full report available at: http://cecsweb.dartmouth.edu/release1.1/datatools/bench_sl.php

In the American health care system, hospitals receive money for services from a variety of sources. The amount of reimbursement for the same service varies by payor. Hospitals make money by treating patients for acute, episodic needs within the hospital and then discharging them as quickly as possible and avoiding readmissions.

Although many programs have realized the financial incentive of promoting palliative care as a way to reduce length of stay and ancillary costs, the challenge is that the current setting-specific or “siloed” payment systems are not designed to support the needs of the populations using the health care system—those with chronic and advanced illness. Therefore, individuals may remain in the hospital, where they receive expensive interventions that are unwanted, unnecessary, or even futile and are frequently readmitted since few have alternatives to receive care outside of the hospital.

In addition, insurance programs currently do not reimburse for palliative care services. For example, insurance programs reimburse practitioners for seeing seriously ill individuals in the hospital when the visit entails a physical exam, a chart review, and/or reading lab tests, but not for a discussion about goals of care for that hospitalization, psychosocial support for the patient and family, or planning future care.

LONG-TERM CARE

Much of the care for people who are seriously ill, especially those who are older, is provided in skilled nursing facilities. Such facilities may be paid by private funds, long-term health care insurance, health insurance, Medicare, and/or Medicaid. According to the Kaiser Family Foundation, Medicare paid 11% of nursing home costs in Pennsylvania in 2003. Medicaid covered 64% of the costs with the remaining 25% paid by private and other sources.

The Medicare skilled nursing facility benefit is specifically designed for short-term rehabilitation patients but not for those who have chronic and progressive long-term needs. The problem with this financial arrangement is that the Medicare benefit to skilled nursing facilities is aligned with rehabilitation goals, which aim for improvement in physical condition and not with the goals of supporting comfort and quality of life in the context of natural decline. One of the greatest barriers for individuals in a long-term care setting, who are in the last phase of life, is that they cannot receive both the Medicare skilled nursing facility benefit and the Medicare hospice benefit simultaneously.

Another barrier to quality care for those at the end of life living in skilled nursing facilities is lack of staff trained to care for these

individuals. While some facilities have implemented programs for dying residents, lack of funding limits access to programs that could provide adequate symptom control and emotional support to both residents and their families.

Because Medicare provides limited coverage, Medicaid is the primary source of payment for long-term living services. When an individual qualifies for Medicaid for nursing facility care, the benefits cover the room and board, supplies, and prescriptions. Pennsylvania currently spends 65.2% of its total Medicaid spending on people living in nursing facilities, compared to 46% nationally. In Pennsylvania, Medicaid recipients in nursing facilities have access to hospice, and payment to the hospice and the nursing facility is paid directly to each provider. This arrangement is a positive aspect of the state's current financing system for nursing facility residents.

HOME AND COMMUNITY-BASED CARE

Pennsylvanians who desire and are able to stay in their homes until their death often receive care from home health care agencies or other community-based services such as those provided by the Area Agencies on Aging and funded through the Pennsylvania Department of Aging 60+ Medical Assistance Waiver Program. These services are paid either fee-for-service or under the prospective payment system by Medicare, Medicaid, public funds, or a combination of those payors. Under Medicare, if an individual is homebound, under a physician's care, and requires medically necessary skilled nursing or therapy services, he or she may be eligible for services provided by a Medicare-certified home health care agency. Likewise, if an individual qualifies for nursing care, but has the ability to stay at home with support, they could qualify for community-based services paid by public funds.

For home care agencies, the prospective payment system has created financial incentives for agencies to reduce lengths of stay and limit the number of home visits. And while Medicare pays home health care agencies a higher rate for patients with greater needs, it is difficult for home care agencies, which specialize in providing palliative care, to build a palliative home care program on this type of payment structure.

Community organizations and services provided by state or county agencies, which provide support for end-of-life care, are part of the long-term living continuum operating in every part of the state. Persons who use this system are generally those

who need help with daily living activities. While this system was not originally designed to provide end-of-life care because of the lack of other resources, it is often the only source of support for people with serious chronic illness living in the community. However, funding is rarely comprehensive and is currently comprised of a patchwork of federal grants, Medicaid, state, and private funding. Small amounts are supplemented from private fees and county governments.

Recommendations to Improve the Financing of Care for the Last Stage of Life

1. Health systems need to redesign routine operations to make it easier for providers to do the right thing, consistent with clinical realities and individuals' values and preferences. For example, incentives to introduce elements of palliative care "upstream" in the course of illness, concurrent with life-prolonging treatment as desired, should be investigated through state-sponsored demonstration projects.
2. State policymakers from the Governor's Office of Health Care Reform, and the Departments of Health, Aging, and Public Welfare should explore new models of care delivery through demonstration projects that focus on redistributing and realigning incentives to provide patient-centered care and quality of life rather than incentives for over-treatment and lengthening of life at all costs.
3. The Departments of Aging and Public Welfare should work to reverse policies that restrict people on the Medicare hospice benefit from also receiving home-based services through the Pennsylvania Department of Aging 60+ Medical Assistance Waiver Program. The hospice benefit is not intended to replace a primary caregiver, rather it should offer the expertise and support needed to live better at the end of life, regardless of the location. Reversing this would also allow those individuals to get services quickly and avoid nursing facility placement.
4. Commercial insurers and hospital systems must invest in palliative care programs in an effort to integrate these services into routine care and thereby 'normalize' them in the continuum of care, as has been done with services like immunizations and preventive mammography.
5. Large employers in Pennsylvania should educate their human resources staff about palliative care and include palliative care and hospice services in company benefit packages offered to employees and retirees as well as support for employees caring for sick and dying family members.

SPECIAL POPULATIONS

While illness and death are universal, attitudes, values, and needs for care during life-limiting illness and near the end of life vary among individuals and groups. The following groups were identified as those whose circumstances, needs, and concerns are not adequately captured by the more general discussions and recommendations in other sections.

OLDER ADULTS

Older people have unique psycho-spiritual needs relative to their age, life experiences, and their perspective on quality of life. Financial concerns, social isolation, care dependence for personal needs, and the prevalence of dementia can create unique challenges for older adults. There is a need to improve cross-generational understanding by providing older people with precise information about end-of-life decision making and informing them of the available community supports.

This population is also likely to experience a compromised physical or mental health status in addition to their terminal condition, making treatment more difficult than in a younger individual.

Two important challenges to successful end-of-life care are the presence of dementia and polypharmacy, which is the use of multiple medications by a patient that often puts older people at risk for adverse drug events.

Recommendations for Older Adults

1. Models of companionship, such as those taught by Ira Byock (www.dyingwell.com), Alan Wolfelt (www.centerforloss.com), and Greg Yoder (www.companionthedying.com), could be a means of assisting in addressing the psycho-spiritual aspects of aging, illness, and death among older people.
2. The combined effect of aging and polypharmacy places older persons at increased risk for adverse drug events, some of which are preventable. To improve outcomes, it is important to eliminate unnecessary medications and restrict medications to those with proven efficacy and minimal adverse effects. Using an evidence-based resource such as the Beers criteria can assist in medication prescribing. Caution is advised when prescribing any medication for this vulnerable population. Due to the potential for adverse drug events, the health care team needs to regularly review medication regimens and opportunities to withdraw unnecessary

medications. At the same time, desire to reduce polypharmacy should not prevent providers from prescribing medications to older persons when they are medically indicated. The quality of care provided and the individual's quality of life may be significantly enhanced by improved prescribing.²

Palliative care should be addressed as an element of care at all long-term living facilities serving this population. State agencies that oversee long-term living facilities should spearhead this initiative in their regulation and survey process.

CHILDREN

According to the Pennsylvania Department of Health, Bureau of Health Statistics and Research, 1,524 children, ages 0-14 died in the State of Pennsylvania in 2002, with an additional 558 deaths of people ages 15-19.³ Statistics provided by the Western Pennsylvania Make a Wish Foundation stated that over 700 children are newly diagnosed with a life-threatening illness each year.

The following are key issues facing children with life-threatening illnesses and their families:

- Limited availability of pediatric palliative and end-of-life care
- Poor symptom management
- Family stress
- Bereavement
- Financial burden and lack of insurance coverage

Specifically, the limited hospice services that are available to children are usually based on guidelines that were intended for adult hospice. In addition, terminally ill children are frequently subjected to a battery of operations and tests in the pursuit of survival, which can engender increased suffering and alienation. Meanwhile, providers are often unaware of appropriate pain management techniques, believing they are limited to children with cancer. The emotional stress of navigating health care services for a terminally ill child can cause families to disintegrate. The parental burden of making life-critical decisions for a suffering child and the ensuing guilt, bereavement, and isolation make the lack of pediatric palliative, hospice, and bereavement care in Pennsylvania all the more egregious.

² Roehl B, Talati A, Parks, S. Medication Prescribing for Older Adults. *Annals of Long-Term Care* 2006, Volume 14, Number 6, 33-39.

³ Department of Health Bureau of Health Statistics and Research. http://www.dsf.health.state.pa.us/health/lib/health/Vital_Stat/2002/2002_statedeath.pdf.

Recommendations for Children

1. The appropriate state agencies, hospital systems, pediatric professionals, and community agencies should work to inform the public more effectively regarding the particular needs of this population and to provide more comprehensive support—educational, financial, and emotional. Anticipatory grief counseling services should be promoted for parents, siblings, and terminally ill children.
2. A statewide Pediatric Palliative and Hospice Task Force should be formed to assess and improve end-of-life services for children.
3. Health care systems should create comprehensive case management programs to assist families with terminally ill children in coordinating their care.
4. Public and private insurers should develop reimbursement that is specific to pediatric palliative and end-of-life services, including benefits permitting home health care nursing in addition to hospice services.

MINORITIES

Barriers to palliative care among minorities arise from specific challenges related to diverse health beliefs, practices, health care access, and utilization patterns during advanced illnesses.

The major barriers for minorities are as follows:

- Health care professionals are not trained to provide culturally competent end-of-life care.
- Some minority groups do not trust the health care industry and underutilize hospice services.
- Linguistic and cultural barriers are not addressed.

Recommendations for Minorities

1. A concerted effort by the medical community, legislators, faith-based organizations, community organizations, and advocacy groups must be made to develop greater training, resources, and outreach vehicles to address this population. Efforts to enhance understanding of cultural diversity and linguistics will improve our ability to provide quality end-of-life experiences to all of Pennsylvania's minorities.
2. Accreditation organizations for the medical community should promote standards for the effective use of language and interpreter services. Hospitals with interpreter services should require training specific to end-of-life care.

3. Educating and involving minority individuals and their faith-based representatives and community leaders in the development of appropriate end-of-life services is key to overcoming cultural barriers.
4. To foster greater trust, long-term goals should include the recruitment of minorities in the medical profession, and their inclusion in all stages of planning and implementing palliative care programs.

DISABILITIES

In general, people with all types of disabilities and their families report feeling devalued by medical professionals. People with disabilities often worry that the health care industry views their lives as less valuable because they have a disability and feel they have little control when it comes to their own health care decisions.

Personal aides or attendants can cause additional problems when they fail to appreciate the perspective of persons with disabilities.

Recommendations for People with Disabilities

1. Persons with disabilities must be better afforded the opportunity to fully direct and control the individual services that they receive.
2. Greater emphasis should be placed on training caregivers for people with disabilities in end-of-life and palliative care services.
3. An individual's right to choose surrogates with the legal authority to make end-of-life decisions must be recognized by law and uniformly practiced. As mentioned earlier in this report, this population has concerns regarding the consistency of the implementation of advance directives. Special education, training, and information should be provided to hospital ethics committees, along with the development of pilot programs to create autonomous independent advocates to assist patients, families, and physicians in difficult end-of-life decisions.
4. Similarly, support and training around respecting informed choices should be available to school personnel, community agency staff, and residential provider staff who serve people with disabilities residing in community living arrangements; to families and friends who provide natural supports to people with disabilities; and to people with disabilities who live independently.
5. People with disabilities should be offered the same treatment options provided to people without disabilities, without discrimination or having decisions made based on health care providers' individual value systems. People with disabilities

should be given the right to make educated choices in regards to pain management such as the right to take a prescription drug for a chronic, pain-causing condition, even if the drug is potentially addictive.

6. State physicians, health care professionals, guardians, judges, and members of ethics committees must be better educated on disability issues.

7. A person with a disability may fear other people's perceptions of what it is like to have a disability especially if the patient is at a point where they cannot express their own wishes.

To address this, each hospital and medical center in the state should have a process to assure that decisions for "Do-Not-Resuscitate" orders reflect the patient's values and preferences.

RURAL COMMUNITIES

Despite the significant rise in the number of medical professionals over the last 25 years, many rural areas in Pennsylvania continue to be dramatically underserved by health care services and professionals. Demographic, geographic, economic, and quality-of-life issues, which are unique to rural areas, can have a significant impact on the health status of rural residents. The following are the primary barriers to serving rural communities:

- Poor geographic access and lack of transportation
- Limited pharmacists to provide medications needed for optimal end-of-life care
- Lack of physician and nurse specialists in hospice and palliative medicine
- Fewer comprehensive, available resources than in urban geographies
- Lack of rural patient home support systems
- Limited income and families at government-established poverty levels

Recommendations for Rural Communities

1. To better address these barriers, Pennsylvania needs to examine financial incentives favoring end-of-life health care providers and systems for rural areas. The state needs to augment existing transportation and create centralized resources for education, utilizing technologies such as teleconferencing.

2. Travel incentives should be offered to medical professionals serving rural communities and travel reimbursement should be offered to patients.

3. Tax or financial incentives should be used to encourage smaller, rural hospitals to adopt palliative and hospice services.

4. A greater emphasis should be placed on appropriate palliative and end-of-life training for rural nursing homes. Rural pharmacists should have access to 24-hour hotlines with current regulations concerning opioids, and assurance of next day delivery of medications used in end-of-life care.

PRISON POPULATIONS

In May 2005, the inmate population of the Pennsylvania Department of Corrections prisons numbered 40,166.

There is a predictably substantial burden of mortality in this population, comparable to that in the U.S. population at large, when adjusted for age, gender, and race.

All state inmates are offered the opportunity to specify end-of-life choices and designate health care proxies. Palliative care is offered to all appropriate patients. Several prisons have highly valued hospice or inmate volunteer programs in which inmates participate in the palliative care of other inmates.

Recommendations for Prison Populations

1. The state penitentiary system requires better coordination with security concerns, education of correctional staff, and the addition of experienced personnel to expand hospice and volunteer programs and to raise the quality of inmates' end-of-life care in general. In addition, it will be necessary to develop some programs using existing personnel.

2. The Department of Corrections' Bureau of Health Care Services should continue its current Hospice Task Force, charged with monitoring palliative and hospice care of inmates.

PROFESSIONAL EDUCATION

National surveys have shown that inadequate preparation is provided on palliative and end-of-life issues in health professionals' education, and data from Pennsylvania mirrors these findings. Educators in a number of health care professions have begun to develop guidelines and model curricula for palliative and end-of-life care, but there is still work to be done. Educational reform is especially relevant to the following professions, and each of these occupations must work together for effective end-of-life care.

- Physicians
- Nurses
- Nursing Aides
- Social Workers
- Physician Assistants
- Chaplains
- Music Therapists
- Art Therapists
- Occupational Therapists
- Speech and Language Therapists
- Nutritionists and Dieticians
- Pharmacists

In particular, education directed toward these professions must encompass the core educational domains of palliative and end-of-life care, which are as follows:

- Communication skills
- Management of pain and other physical symptoms
- Attention to psychological, existential, and spiritual suffering
- Psycho-social aspects of death and dying
- Ethical and legal issues
- Sensitive care for minorities, people with disabilities, and other potentially vulnerable groups
- Interdisciplinary care

Recommendations to Improve Professional Education

1. Organizations that accredit educational institutions and training programs for health care professionals should require them to demonstrate that they incorporate the core educational domains for palliative and end-of-life education. They should also include clinically qualified faculty and ensure trainees are exposed to patients with life-threatening illnesses in contexts that match the clinical environments in which they are likely to be employed.
2. State licensing boards should require that all candidates for licensure or certification provide evidence of a minimum number

of hours of didactic instruction and clinical supervision in the care of patients with life-threatening illness. Continuing education requirements for maintaining licensure or certification should also include a minimum number of hours of approved instruction in the core palliative and end-of-life educational domains. In addition, palliative and end-of-life care content should be included in licensing examinations.

3. Professional organizations at both the national and state levels should design and sponsor continuing and in-service education programs regarding the core end-of-life educational domains. Deans, curriculum committees, and training program directors should ensure that the required curriculum incorporates end-of-life learning objectives in keeping with the standards or recommendations of authoritative professional organizations and national standards.

ADDRESSING THE COMMUNITY

A hundred years ago, death was familiar to family members of all ages. Today, as a result of medical technology, there is limited information about and familiarity with the realities of dying, including options for care that can relieve suffering and distress for both patients and their families.

Based on experience in the field and a review of the literature, key topics have been identified as crucial to improving public understanding:

- Communication about death and dying in the context of significant personal relationships
- Recognition of and support for the lay caregiving experience
- Accurate information about hospice and palliative care
- Accurate information about pain and symptom management

Recommendations

The following recommendations are aimed at increasing public awareness and support for lay caregivers, as well as engaging ordinary Pennsylvanians as proactive advocates of improving palliative care across the Commonwealth:

1. Public Education and Awareness

- Conduct a statewide public awareness campaign to disseminate accurate information about pain management, social support, and the end of life to encourage the public to engage in discussion and planning about these issues and to insist upon excellent professional care. The campaign should use a broad

range of media and, in particular, utilize web-based components to heighten awareness and disseminate information. Information for consumers should include links to programs developed by the End-of-Life Healthcare Project of the National Association of the Attorneys General.

- Conduct a statewide forum on quality care at the end of life along with a series of town meetings and leadership forums to complement the public awareness campaign.
- Implement programs sponsored by civic groups, faith-based organizations, and health care organizations, such as Gunderson Lutheran’s “Respecting Choices,” to help families converse about end-of-life issues.
- Include education on the subject of loss throughout the life cycle at all levels of schooling.

2. Support for Caregivers

- Establish a separate statewide task force to identify systemic approaches to minimize caregiver burden.
- Provide greater support for the psycho-social challenges associated with caregiving through Medicare, Medicaid, medical insurance providers, and community agencies coordinating care.
- Conduct research to test the effectiveness of model projects that empower caregivers through the acquisition of problem-solving and other practical skills.

3. Proactive Consumers

Pennsylvanians should take charge of all aspects of their health care. Some ideas for doing so include the following:

- Create a ‘buddy system’ network wherein local friends agree to safeguard each other’s private health record in case of a medical emergency. The record should include contact information on the next of kin and the designated health care agents, a list of medications, insurance information, copies of any advance care plans, and a brief health history.
- Take notes when visiting health care professionals and reviewing all instructions at the conclusion of the visit.

and accurately, and it must be readily accessible. It is clear that a broad research agenda related to quality at the end of life is beyond the scope and resources of one state alone; therefore, it is recommended that Pennsylvania focus its resources in two areas:

- Collection, analysis, and reporting of existing data and selected data not currently in existence that can be used for surveillance and assessment of trends over time.
- Policy-relevant statewide demonstration projects.

Recommendations

1. Because Pennsylvania’s poor performance on the *Means to a Better End* Report motivated Governor Rendell to convene the Pennsylvania Task Force for Quality at the End of Life, it is logical that it should serve as the starting point for performance tracking, even though the measures for that report are a limited set. Acknowledging this limitation, the authors wrote that they “hope that [the] report will stimulate efforts to improve the availability and quality of the data needed to understand end-of-life care in this country.”

2. The following additional research priorities and data elements are critical to Pennsylvania:

- Proportion of long-term living facility residents who have forms, such as the POLST, or other mechanisms to document residents’ preferences for life-sustaining treatment.
- The frequency that advance directives and orders for treatment limitation are used in long-term living facilities.
- The frequency and timing of “Do-Not-Resuscitate” orders in acute care hospitals.
- Proportion of private health insurance companies that provide some type of coverage for hospice and palliative care and the number of lives that are covered.
- Proportion of Medicaid patients, in addition to dual eligible Medicaid and Medicare patients, who die with covered hospice and/or palliative care services.
- Unique measures for the special populations mentioned earlier, who may be under-represented in broader state data.
- Demonstration and evaluation projects in the context of health care financing and delivery.
- Endorsement of research efforts beyond the scope of the state.

RESEARCH, MEASUREMENT, AND DATA

Data is a powerful tool for assessing needs, detecting problems, and monitoring progress toward solutions, but in order to be useful, it must be the right data. It must be collected consistently

Finally, a population-based survey of quality of care as perceived by bereaved family members of patients who die in Pennsylvania would be the single most direct and meaningful measure of quality at the end of life in our state.

IN CONCLUSION

Our current health care system is not effectively providing comprehensive, coordinated care for those who are seriously ill or at the end of life. Proactive efforts to provide a better balance between acute, cure-oriented approaches and supportive care are needed to maintain the best possible health-related quality of life for seriously ill Pennsylvanians.

Clearly, as the state's older population grows, the issues surrounding the end-of-life experience in Pennsylvania will become of paramount concern. We need to take swift measures in the arenas of palliative care and advance directives. We must dedicate more resources to palliative care education, training, and research, as well as communication about the issues surrounding the end of life. While the recently enacted PA Act 169 signifies an important first step to re-engineer the state's policies regarding transferability, simplification, and consistency of advance directives, without a revision of the current financial matrix, which favors acute care over palliative care, we cannot expect the state to score a better grade during the next national review of end-of-life care.

Ultimately, however, Pennsylvania's challenge is more than poor grades on a report card. These poor grades translate into real suffering for individuals and families. Providing quality end-of-life experiences for all Pennsylvanians is a challenge of increasing urgency, and one that must be tackled by all of us. By working together, legislators, medical professionals, educators, activists, and citizens can address these most basic conditions of human life with the intelligence, compassion, and resources they deserve and ensure that those with a serious illness and at the end of life have access to the care they need to maintain their values, sense of dignity, and quality of life to the greatest extent possible.

1 Levine, C. The loneliness of the long-term care giver. *New England Journal of Medicine*, 1999 340: 1587-1590.

2 Roehl B, Talati A, Parks S. Medication Prescribing for Older Adults. *Annals of Long-Term Care* 2006: Volume 14, Number 6, 33-39.

3 Department of Health Bureau of Health Statistics and Research
http://www.dsf.health.state.pa.us/health/lib/health/Vital_Stat/2002/2002_statedeath.pdf.

DETAILED TASK FORCE RECOMMENDATIONS

NUMBER	RECOMMENDATION	TIMELINE
COMMUNICATING WISHES FOR CARE		
RECOMMENDATIONS FOR BETTER ADVANCE CARE PLANNING		
1.	The Legislature should update advance directive law to assist in empowering surrogates, assigning default surrogates, broadening the legal definitions surrounding terminal illness, standardizing and simplifying advance directive procedures and forms, and mandating the development of a statewide, HIPAA-compliant registry for advance directives.	Short Term (1-2 years)
2.	The Department of Health should adopt a portable form like the Physician Orders for Life-Sustaining Treatment (POLST) to augment the transferability of advance care plans. The form accompanies patients across health care settings to ensure that their wishes are honored throughout the health care system.	Intermediate (3-4 years)
3.	To address issues of reimbursement for advance care planning with patients, medical insurance coverage should provide reimbursement incentives for physicians to have the extended conversations that are required for advance care planning, and the Insurance Department should work with practitioners who participate in Medicare and Medicaid to be adequately reimbursed for the time they spend discussing advance directives with patients.	Intermediate (3-4 years)
PROVISION OF CARE		
RECOMMENDATIONS FOR IMPROVING PALLIATIVE CARE		
4.	The Pennsylvania Medical Society and Pennsylvania State Nurses Association, in collaboration with the Pennsylvania Hospice Network, should create a web-based statewide clearinghouse for palliative care professionals, including standardized best practices, information, and resources.	Short Term (1-2 years)
5.	The Pennsylvania Department of State should require evidence of baseline education in palliative care tied to professional state licensure [physician, nurse, allied health providers].	Intermediate (3-4 years)
6.	The Pennsylvania legislature should increase funding for scholarships, offer incentives for advanced training or certification in palliative care such as the End-of Life Nursing Education Consortium (ELNEC) and the Education on Palliative and End-of-Life Care (EPEC) programs, or board certification.	Intermediate (3-4 years)
7.	The Department of State should adopt the Federation of State Medical Board's <i>Model Guidelines for the Use of Controlled Substances for the Treatment of Pain</i> .	Intermediate (3-4 years)
RECOMMENDATIONS FOR IMPROVING COORDINATION OF CARE		
8.	The Pennsylvania Department of Health should encourage standardization of medical record keeping and information transmission by providing support for health care institutions moving to an electronic medical record system, which can be accessed by multiple providers.	Long Term (5 or more years)

NUMBER	RECOMMENDATION	TIMELINE
9.	The Pennsylvania Department of Health should work with accrediting bodies such as the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) and the Community Health Accreditation Program (CHAP) to mandate initiatives such as the POLST and the Medication Reconciliation Program to improve quality of care across settings.	Intermediate (3-4 years)
RECOMMENDATIONS FOR INCREASING PALLIATIVE CARE SPECIALISTS IN HEALTH CARE FACILITIES		
10.	The Pennsylvania Department of Health, Pennsylvania Health Care Cost Containment Council (PHC4), insurers, and hospitals/health care systems should create incentives for broader creation and utilization of palliative care teams that include public reporting of hospitals and nursing homes offering these services.	Intermediate (3-4 years)
11.	In order for facilities to receive licensure, the Department of Health should mandate professional education in palliative care for acute and long-term care staff including the medical director, staff physicians, nursing personnel, social workers, and pastoral care staff. Staff education should incorporate a palliative care and end-of-life curriculum that follows current guidelines established by the National Consensus Project (NCP) into the competencies for staff.	Intermediate (3-4 years)
12.	The Department of Health should revise regulatory guidelines for long-term care facilities by requiring that palliative care principles and practices are included in domains of licensure for nursing facilities and by providing training to all state surveyors on those principles.	Intermediate (3-4 years)
13.	The Department of Health, in collaboration with the Department of Public Welfare, should commission a study to test the hypothesis that increased patient-to-staff ratios in long-term care facilities to improve care and outcomes for residents who are seriously ill and at the end of life.	Intermediate (3-4 years)
14.	To improve end-of-life care, long-term care facilities should consider offering more training to staff or contracting with local hospice providers for their expertise.	Intermediate (3-4 years)
RECOMMENDATIONS FOR IMPLEMENTING PALLIATIVE CARE STANDARDS		
15.	The Governor should identify one agency to have overall responsibility for ensuring that all health care providers and local governments are made aware of and follow the national standards set forth in the NCP's <i>Clinical Care Practice Guidelines for Quality Palliative Care</i> and the National Quality Forum's (NQF's) <i>A National Framework for Palliative and Hospice Care Quality Measurement and Reporting</i> .	Short Term (1-2 years)
16.	Since national standards are continually evolving, the agency identified by the Commonwealth should regularly monitor developments in both the NCP and NQF.	Intermediate (3-4 years)

NUMBER	RECOMMENDATION	TIMELINE
17.	The responsible agency should develop creative incentives to encourage and support the standards, provide education about them, and leverage the weight and authority of the Commonwealth's authority to make the case for their adoption.	Intermediate (3-4 years)
18.	The agency should ensure that once the NQF has developed and formally released its quality indicators for palliative care (expected release in 2008), these indicators are subsequently incorporated into new and existing health care programs throughout the Commonwealth.	Long Term (5 or more years)
FINANCING CARE		
RECOMMENDATIONS FOR HEALTH CARE SYSTEMS AND PROVIDERS		
19.	The Pennsylvania Medical Society, Hospital and Health System Association of Pennsylvania and the Pennsylvania Hospice Network should encourage their members to redesign routine operations to make it easier for providers to do the right thing consistent with clinical realities and individuals' values and preferences. For example, incentives to introduce elements of palliative care "upstream" in the course of illness, concurrent with life-prolonging treatment as desired, should be investigated through state-sponsored demonstration projects.	Intermediate (3-4 years)
20.	Hospital systems and insurers should invest in palliative care programs in an effort to integrate these services into routine care to 'normalize' it in the continuum of care, similarly to what has been done with services like immunizations and preventive mammography.	Intermediate (3-4 years)
RECOMMENDATIONS FOR THE COMMONWEALTH OF PENNSYLVANIA		
21.	State policymakers from the Office of Health Care Reform, and the Departments of Health, Aging, and Public Welfare should explore new models of care delivery through demonstration projects that focus on redistributing and realigning incentives to provide patient-centered care and quality of life rather than incentives for over-treatment and lengthening of life at all costs.	Intermediate (3-4 years)
22.	The Departments of Aging and Public Welfare should reverse the decision that restricts people on the Medicare hospice benefit from also receiving home-based services through the Pennsylvania Department of Aging (PDA) waiver program and reinstate Community Choice for people in need of waiver services and the Medicare hospice.	Short Term (1-2 years)
23.	The Governor's office, along with the Office of Health Care Reform, and the Departments of Health, Aging, and Public Welfare should work with the Center for Medicare and Medicaid Services (CMS) to consider reimbursement for palliative care providers, and organizations that provide those services.	Intermediate (3-4 years)

NUMBER	RECOMMENDATION	TIMELINE
24.	The Department of Public Welfare should make the coverage expectations consistent for Medicaid HMOs and straight Medicaid, perhaps as a ‘carve out’ as was done for Medicare HMOs, reverting to a direct relationship between the hospice provider and the Department of Welfare.	Long Term (5 or more years)
25.	The Department of Aging should simplify the interface of existing benefits of services like Hospice Medicare/Medicaid Benefits and the PDA Waiver, to allow for maximum support to patients and families who are both living with a serious, chronic illness and trying to stay out of a nursing home.	Intermediate (3-4 years)
26.	The Governor’s Office, the Office of Health Care Reform, and the Insurance Department should work with the legislature to evaluate the potential impact on overall health care costs and premium costs of a state mandate that private health insurers cover hospice and palliative care services as part of the basic benefit package. This evaluation should use simulations based upon data from insurers currently covering and not covering these services.	Long Term (5 or more years)
27.	The Insurance Department should work with practitioners who participate in Medicare and Medicaid to be adequately reimbursed for their time spent providing symptom management and care coordination for people with life-threatening illnesses and in the last phase of life.	Long Term (5 or more years)
28.	Department of Public Welfare should request a waiver from the CMS to provide Medicaid benefits to qualifying individuals for personal care.	Intermediate (3-4 years)
29.	The Office of Healthcare Reform and insurance plans looking for innovative reform to Medicare and Medicaid and other insurance plans to provide better palliative and end-of-life care should consider expanding the availability of waiver programs.	Intermediate (3-4 years)
30.	The Department of Public Welfare should change the technical requirements for Medicare and Medicaid hospice benefits to be more consistent.	Intermediate (3-4 years)
RECOMMENDATIONS FOR COMMERCIAL HEALTH INSURERS		
31.	Current incentives for commercial managed care favor healthier beneficiaries who need less care and fewer services. Private health plans and insurers in Pennsylvania should take a lead in demonstrating outcomes for sick patients (both adult and pediatric) by pioneering the design of a risk adjuster for members who meet those criteria.	Intermediate (3-4 years)
32.	Medicare managed care plans should adopt more flexibility in funding innovative, creative models of integrated end-of-life care and palliative care delivery that are less constrained by the restrictions imposed by the Medicare hospice benefit and more responsive to their end-of-life populations.	Intermediate (3-4 years)
33.	Pennsylvania insurance plans should adequately reimburse practitioners for the time they spend providing symptom management and care coordination for patients with life-threatening illnesses and in the last phase of life.	Long Term (5 or more years)

NUMBER	RECOMMENDATION	TIMELINE
34.	Medicare managed care plans in Pennsylvania should pay hospitals for palliative care as part of their incentive programs by changing the palliative care Diagnosis Related Group (DRG) from merely a coding and tracking DRG to one that provides reimbursement to hospitals.	Long Term (5 or more years)
RECOMMENDATIONS FOR EMPLOYERS AND THE PUBLIC		
35.	Employers in Pennsylvania should educate their Human Resources staff and/or employees about palliative care and include palliative care and hospice services in company benefit packages offered to employees and retirees as well as programs for employees caring for sick and dying family members.	Short Term (1-2 years)
36.	The Insurance Department should encourage or require employers to offer educational programs for their employees regarding palliative care options.	Short Term (1-2 years)
37.	The Insurance Department should work with consumers to become educated about the benefits that their health plan offers.	Short Term (1-2 years)
RECOMMENDATIONS FOR CONSUMER ADVOCACY ORGANIZATIONS		
38.	Consumer advocacy organizations should offer education to consumers regarding how services such as palliative care, hospice, and advance care planning can be reimbursed.	Short Term (1-2 years)
39.	Consumer advocacy organizations should develop statewide strategies to educate families about the costs and financial supports required to care for someone who is seriously ill.	Intermediate (3-4 years)
SPECIAL POPULATIONS		
<i>Older Adults</i>		
RECOMMENDATIONS FOR RESPECTING THE PERSPECTIVE OF OLDER ADULTS		
40.	Public information campaigns designed to improve access to palliative care and end-of-life services should be created with particular attention to the life-situation, information needs, and cognitive abilities of older adults.	Intermediate (3-4 years)
41.	To address the psycho-spiritual aspects of aging, illness, and death, models of companionship should be promoted.	Intermediate (3-4 years)
42.	State chapters of organizations devoted to advocating for older adults and for the needs of people with conditions prevalent among older adults, (e.g., Alzheimer’s Association) should be encouraged to create a guideline booklet directed towards end-of-life care for both professionals and family members.	Short Term (1-2 years)

NUMBER	RECOMMENDATION	TIMELINE
RECOMMENDATIONS FOR MEETING THE COMPLEX MEDICAL NEEDS OF OLDER ADULTS		
43.	Hospice agencies should promote the understanding that hospice provides services for dementia-related diagnoses and is not strictly for cancer or other more acute medical conditions.	Short Term (1-2 years)
44.	Pharmacies should offer programs in which older adults can bring in all of their medications for review in order to combat polypharmacy.	Short Term (1-2 years)
45.	Pharmacists and other health providers should educate older adults on the myths and facts of pain management, especially the use of opioids, and address fears of addiction.	Intermediate (3-4 years)
46.	Where supported by evidence, educational efforts should provide older adults with information regarding the benefits of complementary medicine for palliative care.	Intermediate (3-4 years)
47.	Long-term care facilities should be accountable for quality and comprehensive end-of-life care through the establishment of focused palliative care programs.	Intermediate (3-4 years)
RECOMMENDATIONS FOR THE STATE SURVEY PROCESS		
48.	Develop a standardized definition of palliative care/terminal care so differing medical venues, agencies, and long-term care facilities can use the same language in talking about end of life.	Intermediate (3-4 years)
49.	Require that the survey process focus on individualized care for the dying and acknowledge medical and spiritual realities associated with end of life such as weight loss, the need for aggressive pain control, decline in physical and social functioning, and life completion tasks. The Department of Public Welfare should change the technical requirements for Medicare and Medicaid hospice benefits to be more consistent.	Intermediate (3-4 years)
50.	Surveyors should inquire during surveys about staff training on end-of-life care and pain management protocols.	Short Term (1-2 years)
51.	Surveyors should attend mandatory end-of-life training.	Short Term (1-2 years)
52.	Educate surveyors on the strengths of culture change models within long-term care. These philosophies of care put resident needs at the center of care planning and decision making [e.g., the Eden Alternative (www.edenalternative.com), the Pioneer Network (www.pioneernetwork.net)].	Short Term (1-2 years)
RECOMMENDATIONS FOR IMPROVED PALLIATIVE CARE SERVICES		
53.	Administrators of facilities should insure that existing research on older adults and end-of-life issues is readily available and accessible to personnel working with older adults in hospices, nursing homes, assisted living facilities, prisons, community centers, hospitals, and psychiatric institutions.	Short Term (1-2 years)
54.	Facilities should distribute end-of-life and hospice literature as part of the admission process.	Short Term (1-2 years)

NUMBER	RECOMMENDATION	TIMELINE
55.	Facilities should develop care plan meeting procedures that engage in periodic conversation and review of a resident’s advance care planning with both the resident, as capability allows, and the responsible party.	Short Term (1-2 years)
56.	The Pennsylvania Department of Aging should pilot an Elder Health Care Advocacy Program as an expansion of the current PA State Long-Term Care Ombudsman Program that is managed through the Area Agencies on the Aging. The goal would be to provide and advocate for individuals who do not have an advance directive or surrogate decision-maker to oversee communication of health information to assure that the individual’s needs are being met.	Intermediate (3-4 years)
57.	The Pennsylvania Medical Directors Association (PMDA) should unite with the Pennsylvania Hospice Network and hospice agencies within the state to target older adults and their caregivers with hospice awareness and education.	Intermediate (3-4 years)
<i>Pediatric Populations</i>		
RECOMMENDATIONS TO IMPROVE AVAILABILITY OF PEDIATRIC PALLIATIVE AND END-OF-LIFE CARE SERVICES		
58.	The appropriate state agencies, hospital systems, pediatrics professionals, and community agencies should work to inform the public more effectively regarding the particular needs of this population and to provide more comprehensive support (e.g., educational, financial, emotional). Anticipatory grief counseling services should be promoted for parents, siblings, and terminally ill children.	Intermediate (3-4 years)
59.	The appropriate state agencies should create a statewide Pediatric Palliative and Hospice Care Task Force to assess the needs of children and families across the state.	Short Term (1-2 years)
60.	Pennsylvania hospitals that care for critically ill children should create palliative support services.	Intermediate (3-4 years)
61.	Hospice agencies should provide in-service education to staff to ensure competency of care for children.	Short Term (1-2 years)
RECOMMENDATIONS TO IMPROVE POOR SYSTEM MANAGEMENT		
62.	Incorporate information specific to medically fragile and terminally ill children in the core domains of health professionals’ end-of-life education.	Long Term (5 or more years)
63.	Community and family outreach programs should include education for families regarding pain and symptom management for children.	Intermediate (3-4 years)
64.	Support for early referrals for pediatric palliative care should be included as hospitals and insurers invest in integrating palliative care services and programs into routine care to ‘normalize’ it in the continuum of care.	Intermediate (3-4 years)

NUMBER	RECOMMENDATION	TIMELINE
RECOMMENDATIONS TO REDUCE FAMILY STRESS		
65.	Incorporate education regarding family-centered care within the palliative and hospice care models in the core domains of health professionals' end-of-life education.	Long Term (5 or more years)
66.	Health care organizations and insurers should examine how to create comprehensive case management programs to assist families in successfully navigating and coordinating their child's care.	Intermediate (3-4 years)
67.	Anticipatory grief and bereavement for families and the community affected by the loss of a child should be incorporated in the core educational domains of health professionals' end-of-life education.	Intermediate (3-4 years)
RECOMMENDATIONS TO AMELIORATE FINANCIAL BURDEN AND LACK OF INSURANCE COVERAGE		
68.	Public and private health insurers should create reimbursement for palliative and end-of-life services that are specific to pediatrics and not solely dictated by Medicare guidelines.	Intermediate (3-4 years)
<i>Minorities</i>		
RECOMMENDATIONS TO FOSTER INCLUSION OF MINORITY COMMUNITIES		
69.	Entities with the mandate of improving end-of-life care for minorities (e.g., Department of Aging, Office of Minority Health) should work toward developing culturally informed reference materials on specific minority subgroups that can be accessed by health professionals.	Short Term (1-2 years)
70.	The materials referred to under recommendation number 69 should be generated to provide a general understanding of end-of-life care needs of specific minority subgroups, while avoiding the cookbook approach and encouraging health professionals to validate this information with patients and families.	Short Term (1-2 years)
71.	Training workshops on end-of-life care for health professionals must involve members of ethnic minorities, faith-based leaders, and community leaders to assist in planning and implementation of the workshops.	Intermediate (3-4 years)
72.	Health care entities must develop hospital/hospice-community networks involving faith-based leaders of different faiths, [e.g., a rabbi (Jewish), a chaplain or priest (Christian), or imam (Muslim)] who can be called upon for advice pertaining to difficult terminal care situations and for improving patient and family support during end-of-life situations.	Intermediate (3-4 years)
RECOMMENDATIONS TO FOSTER TRUST AMONG UNDERSERVED GROUPS		
73.	Development of any palliative care program must follow a "bottom-up," not "top-down" approach.	Short Term (1-2 years)
74.	The state should fund pilot projects that involve the minority community in planning appropriate educational and clinical programs in palliative care.	Intermediate (3-4 years)
75.	A long-term goal should be the recruitment of more minority providers in delivering health care in general and palliative and hospice care in particular.	Long Term (5 or more years)

NUMBER	RECOMMENDATION	TIMELINE
RECOMMENDATIONS TO ENCOURAGE UTILIZATION OF PALLIATIVE AND HOSPICE SERVICES BY MINORITY POPULATIONS		
76.	Campaigns should be created involving individuals from the community as palliative and hospice care educators, spokespersons, outreach workers, and liaisons.	Intermediate (3-4 years)
77.	The goal of the campaigns should be to increase community awareness about hospice and palliative care programs and not simply to increase enrollment into hospice programs.	Intermediate (3-4 years)
78.	Training programs must involve both minority and non-minority individuals to prevent an inadvertent perception that efforts are targeted to increase minority patients' enrollment into hospice programs.	Short Term (1-2 years)
RECOMMENDATIONS TO OVERCOME LINGUISTIC BARRIERS AND PROVIDE TIMELY AND EFFECTIVE CARE FOR PATIENTS WITH LIMITED ENGLISH PROFICIENCY		
79.	State accreditation agencies for health care organizations should promote standards for the use of effective language and interpreter services for patients with Limited English Proficiency in Pennsylvania.	Short Term (1-2 years)
80.	The above can be achieved by learning from other states' initiatives in language interpretation programs and by interacting with other organizations.	Short Term (1-2 years)
81.	Hospitals employing medical interpreters should provide them with training on issues and challenges specific to palliative and end-of-life care.	Intermediate (3-4 years)
82.	Hospitals and other health care institutions should develop a repository of reference materials related to hospice and palliative care in commonly spoken languages in Pennsylvania.	Short Term (1-2 years)
<i>Disabilities</i>		
RECOMMENDATIONS TO FOSTER INCLUSIONS OF INDIVIDUALS WITH DISABILITIES		
83.	Health care providers should offer people with disabilities the same treatment options provided to people without disabilities, without discrimination or decisions based on health care providers' individual value systems. People with disabilities should be given the right to make educated choices in regards to pain management such as the right to take a prescription drug for a chronic, pain-causing condition, even if the drug is potentially addictive.	Short Term (1-2 years)
84.	Greater emphasis should be placed on training caregivers for people with disabilities in end-of-life and palliative care services.	Short Term (1-2 years)
85.	Any training in this area must include input from and collaboration with people who are receiving the service in question, and only people receiving the services qualify as consumers of said service.	Short Term (1-2 years)

NUMBER	RECOMMENDATION	TIMELINE
86.	Support and training around making and respecting informed choices should be made available to the following: <ul style="list-style-type: none"> • School personnel. • Community agency staff and residential provider staff who serve people with disabilities residing in community living arrangements. • Families and friends who provide natural supports to people with disabilities, particularly to the families of children with disabilities. • People with disabilities who live independently. 	Intermediate (3-4 years)
87.	State agencies responsible for support and assistance to people with disabilities should establish a clearinghouse of information and decision-making support.	Short Term (1-2 years)
88.	Pennsylvania’s physicians, health professionals, guardians, judges, and members of ethics committees should be trained on disability issues using programs developed by the disabilities communities.	Intermediate (3-4 years)
89.	The perspectives and concerns of people with disabilities should be incorporated in the core domains of education for health professionals.	Short Term (1-2 years)
90.	Processing parameters, but not set answers, must be developed to address certain cases where people invoke their “right to refuse” treatment.	Long Term (5 or more years)
91.	Administrators of health care institutions should regularly reinforce to all employees that withholding a service or a choice based solely on the fact of a person’s disability is discrimination.	Short Term (1-2 years)
92.	Each hospital and medical center in the state should have a process in place to assure that decisions for “Do-Not-Resuscitate” orders reflect the patient’s values and preferences.	Intermediate (3-4 years)
93.	Decisions for “Do-Not-Resuscitate” orders should be made only with the joint participation of the doctor and patient and/or health care power of attorney and the participation of any significant others of the patient’s choice.	Short Term (1-2 years)
94.	Clear and truthful communication of both the risks and benefits of treatment or the withholding of treatment must be provided and documented.	Intermediate (3-4 years)
95.	A policy should exist that offers a Hospital Ethics Committee consultation when “Do-Not-Resuscitate” orders are discussed to provide support for the difficult decision-making process.	Intermediate (3-4 years)
96.	Hospital Ethics Committees throughout the state should receive education about issues related to the special concerns of the disabled.	Intermediate (3-4 years)
97.	Hospitals should conduct an annual audit to review end-of-life treatment of those patients admitted with primary or secondary diagnoses of paraplegia, quadriplegia, cerebral palsy, multiple sclerosis, profound retardation, and other conditions on a list formulated with the participation with members of the disabilities community to assure adherence with the treatment choices of the individual who died.	Intermediate (3-4 years)

NUMBER	RECOMMENDATION	TIMELINE
98.	The state should fund pilot programs that utilize advocates/ombudsmen to assist patients, families, and physicians in difficult end-of-life decisions, including for “Do-Not-Resuscitate” orders, and evaluate their effectiveness.	Intermediate (3-4 years)
99.	An individual's right to choose who participates in decisions on their behalf (and who should not participate) must be recognized in law and uniformly respected in practice.	Intermediate (3-4 years)
100.	Long-term pain management should be built into pain clinics as well as other health settings, such as doctors’ offices.	Intermediate (3-4 years)
101.	If a person with a disability receiving state and/or Medicaid-funded services becomes terminally ill, the provider should ensure the consumer and the consumer’s primary caretaker are made aware of such services as emotional grief counseling.	Intermediate (3-4 years)
102.	Additional focus groups should be held to gather further input on the issues addressed in the above recommendations, in particular as they pertain to children, those who are medically fragile and non-verbal, and to people with disabilities who reside in institutions.	Short Term (1-2 years)
103.	At future forums on this issue, people with mental retardation should be invited to participate.	Short Term (1-2 years)
104.	The Task Force should be expanded to increase its representation of people with disabilities.	Short Term (1-2 years)
<i>Rural Communities</i>		
RECOMMENDATIONS FOR FINANCING		
105.	Hospice reimbursement schemes should offer additional compensation for providers who travel longer distances to serve rural patients.	Short Term (1-2 years)
106.	Medical Assistance and Medicare should improve reimbursements for palliative medicine diagnosis codes and home-care codes delivered in a rural setting.	Intermediate (3-4 years)
107.	The Departments of Health and Aging should provide grants for rural hospitals to offer educational programs such as EPEC, for physicians, and ELNEC, for nurses, to provide practitioners with the basic knowledge and skills related to end-of-life care.	Intermediate (3-4 years)
108.	There should be state support for loan forgiveness for individuals practicing palliative medicine in rural sites.	Intermediate (3-4 years)
109.	Public and private insurers should develop financial incentives for community hospitals without palliative care expertise to develop teleconferencing relationships with certified palliative and hospice medicine specialists at other clinical centers.	Intermediate (3-4 years)

NUMBER	RECOMMENDATION	TIMELINE
110.	Public and private insurers should offer outlier payments for hospices in rural areas to support adult daycare programs and small rural hospitals and extended care facilities to develop palliative care programs.	Intermediate (3-4 years)
RECOMMENDATIONS FOR COMMUNITY SUPPORT		
111.	A centralized state hotline is needed for pharmacists to request assistance with current regulations regarding the use of opioids and other controlled substances for end-of-life and hospice care.	Intermediate (3-4 years)
112.	A statewide consortium of pharmacists should develop medication lists needed for end-of-life care, with a central state repository to assure next day delivery of medications used in end-of-life care.	Intermediate (3-4 years)
113.	Professional societies such as the Hospice and Palliative Nurses Association (HPNA) and the American Academy of Hospice and Palliative Medicine (AAHPM) should develop regional palliative medicine meetings and Continuing Medical Education (CME) and Continuing Education (CEU) courses throughout the state.	Intermediate (3-4 years)
114.	Educational programs should target rural nursing homes.	Intermediate (3-4 years)
<i>Prison Populations</i>		
115.	Encourage internal development of local prison palliative care services, utilizing facilitators and trainers with correctional experience and local inmate volunteers.	Intermediate (3-4 years)
116.	Expand end-of-life educational activities for security and health care staff.	Intermediate (3-4 years)
117.	Continue oversight of the program by Hospice Task Force.	Intermediate (3-4 years)
PROFESSIONAL EDUCATION		
RECOMMENDATIONS TO ACCREDITING BODIES		
118.	Organizations that accredit educational institutions or training programs for health professionals should require such institutions or programs to demonstrate that the core educational domains for end-of-life education (i.e., communication skills; management of pain and other symptoms; attention to psychological, existential, and spiritual suffering; psycho-social aspect of death and dying; ethical and legal issues; and sensitive care for vulnerable groups) are incorporated into the curriculum as appropriate to the particular profession.	Intermediate (3-4 years)
119.	To receive accreditation, educational institutions should include clinical qualified faculty who are competent to teach the core domains.	Intermediate (3-4 years)
120.	To receive accreditation, educational institutions should be required to demonstrate that trainees are exposed to patients with life-threatening illnesses in all clinical environments in which graduates are likely to be employed.	Intermediate (3-4 years)

NUMBER	RECOMMENDATION	TIMELINE
RECOMMENDATIONS TO STATE LICENSING BOARDS		
121.	To receive accreditation, educational institutions must require that graduates demonstrate competence in the core educational domains as a prerequisite to graduation.	Intermediate (3-4 years)
122.	State Licensing Boards for the various professions should require all candidates for licensure or certification to provide evidence of a minimum number of hours of didactic instruction and clinical supervision at an accredited institution in the care of patients with life-threatening illnesses.	Intermediate (3-4 years)
123.	Licensing or certification examinations should include questions that address the core end-of-life educational domains.	Intermediate (3-4 years)
124.	Annual continuing education requirements for maintaining licensure or certification should include a minimum number of hours of approved instruction in the core end-of-life educational domains.	Intermediate (3-4 years)
RECOMMENDATIONS TO PROFESSIONAL ORGANIZATIONS		
125.	Professional organizations at the national level should define the standards of professional competency in end-of-life care expected for trainees at every level of education in their profession.	Intermediate (3-4 years)
126.	Professional organizations should convene expert consensus panels to develop and disseminate learning objectives and model curricula in end-of-life care for implementation by training programs.	Intermediate (3-4 years)
127.	Examinations for admission to specialty practice should include questions on content in the core end-of-life educational domains.	Intermediate (3-4 years)
128.	Professional organizations at both the national and state levels should design and sponsor continuing education programs (e.g., lectures, workshops, seminars, symposia) in the core end-of-life educational domains at local, state, and regional meetings.	Intermediate (3-4 years)
129.	Organizations at the national and state levels should create end-of-life education modules for use by in-service education programs in hospitals, clinics, and long-term institutions.	Intermediate (3-4 years)
130.	Organizations at the national and state levels should sponsor train-the-trainer educational programs for faculty with responsibility for end-of-life instruction.	Short Term (1-2 years)
RECOMMENDATIONS TO DEANS OF HEALTH PROFESSIONS SCHOOLS		
131.	Deans of health professions schools should ensure that their curriculum includes all relevant core end-of-life educational domains.	Short Term (1-2 years)
132.	The senior faculty should include specialists in end-of-life care.	Short Term (1-2 years)
133.	All faculty who teach students in settings that involve the care of patients with life-threatening illnesses should receive training in the content and pedagogical methods of end-of-life care.	Intermediate (3-4 years)

NUMBER	RECOMMENDATION	TIMELINE
RECOMMENDATIONS TO CURRICULUM COMMITTEES AND TRAINING PROGRAM DIRECTORS		
134.	Curriculum committees and training program directors should ensure that the required curriculum incorporates the end-of-life learning objectives in the core educational domains, and that the curriculum meets the standards or recommendations of authoritative professional organizations.	Intermediate (3-4 years)
135.	The required end-of-life curriculum should include both the cognitive and affective domains, and encompass didactic instruction, experiential learning, supervised clinical practice, and opportunities for self-reflection.	Intermediate (3-4 years)
136.	Trainees should be evaluated on their knowledge, attitudes, and clinical competence in the core domains of end-of-life care with satisfactory performance as a requirement for promotion and graduation.	Intermediate (3-4 years)
RECOMMENDATIONS TO INSTRUCTORS		
137.	Faculty responsible for end-of-life education should attend train-the-trainer seminars to learn state-of-the-art methods of end-of-life teaching.	Intermediate (3-4 years)
138.	Faculty should be familiar with print and electronic educational resources for end-of-life care.	Short Term (1-2 years)
139.	Faculty should be aware of the emotional reactions common to trainees who interact with critically ill and dying patients and be able to help students process their reactions constructively.	Short Term (1-2 years)
140.	Faculty in all disciplines should include appropriate examples and clinical scenarios related to patients near the end of life to illustrate core principles in their discipline and include end-of-life content in examinations.	Intermediate (3-4 years)
THE COMMUNITY		
141.	A public/private partnership with government agencies, consumer organizations, provider organizations, and insurers should develop or support the development of a website for consumers on palliative care and end-of-life resources followed by the development of a statewide consumer awareness and education campaign.	Short Term (1-2 years)
142.	The Governor's Office, the Departments of Aging and Health, and the Office of Health Care Reform, in collaboration with public broadcasting stations and other media outlets including commercial television, radio, and newspapers, should implement a statewide public awareness campaign. The goal of this campaign would be to help Pennsylvanians become more informed about palliative care, and death and dying and to become proactive consumers of quality health care services.	Intermediate (3-4 years)
143.	Appropriate state agencies should complement the public awareness campaign with a statewide forum on quality care at the end of life along with a series of town meetings and leadership forums.	Short Term (1-2 years)

NUMBER	RECOMMENDATION	TIMELINE
144.	Develop a state-supported coalition, which is facilitated and organized through civic groups, and faith-based and health care organizations throughout the Commonwealth, that models Gundersen Lutheran’s “Respecting Choices” program.	Intermediate (3-4 years)
145.	Educators should cover the subject of loss throughout the life cycle at all levels of schooling.	Intermediate (3-4 years)
146.	A statewide task force organized by Department of Health should be convened to identify systemic approaches to minimize caregiver burden.	Intermediate (3-4 years)
147.	Members of the public at large are encouraged to “take charge” of all aspects of their health care by creating a “buddy system” network, wherein local friends agree to safeguard each other’s private health record in case of a medical emergency, taking notes when visiting health professionals, and reviewing all instructions at the conclusion of visits.	Intermediate (3-4 years)
148.	CMS, along with the Departments of Public Welfare and Health, medical insurance providers, and community agencies coordinating care should provide consumers with support for the psycho-social challenges associated with caregiving that help families access and negotiate for services, equipment, medicine, etc.	Intermediate (3-4 years)
149.	Pennsylvania’s Attorney General should join other state attorneys general who are providing links to end-of-life information for consumers and other programs developed by the End-of-Life Health Care Project of the National Association of Attorneys General.	Short Term (1-2 years)
150.	The Commonwealth of Pennsylvania should issue Requests for Proposals for researchers throughout the state to design and test the effectiveness of model projects that empower caregivers through the acquisition of problem-solving and other practical skills.	Intermediate (3-4 years)
RESEARCH, MEASUREMENT, AND DATA		
151.	<p>Pennsylvania should focus its resources in the following two public health principles of surveillance and quality assurance:</p> <ul style="list-style-type: none"> • Collection, analysis, or reporting of existing data and selected data not currently in existence that can be used for surveillance and assessment of trends over time. • Policy-relevant statewide demonstration projects. 	Short Term (1-2 years)
152.	The Last Acts <i>Means to a Better End</i> Report should serve as the starting point for performance tracking, even though the measures for that report are a limited set.	Short Term (1-2 years)

NUMBER	RECOMMENDATION	TIMELINE
153.	<p>The following additional research priorities and data elements are critical to Pennsylvania:</p> <ul style="list-style-type: none"> • Proportion of long-term living facility residents who have forms, such as the POLST, or other mechanisms to document residents’ preferences for life-sustaining treatment. • The frequency of advance directives and orders for treatment limitation in long-term living facilities. • The frequency and timing of “Do-Not-Resuscitate” orders in acute care hospitals. • Proportion of private health insurance companies that provide some type of coverage for hospice and palliative care and the number of lives that are covered. • Proportion of Medicaid patients, in addition to dually eligible Medicaid and Medicare patients, who die with covered hospice and/or palliative care services. • Unique measures for the special populations mentioned earlier, who may be under-represented in broader state data. • Demonstration and evaluation projects in the context of health care financing and delivery. • Endorsement of research efforts beyond the scope of the state. 	Intermediate (3-4 years)
154.	The Governor should mandate that the Pennsylvania Department of Health and Department of Aging jointly prepare a “State of End-of-Life Care” report every two years to describe ongoing state initiatives and to track changes over time.	Short Term (1-2 years)
155.	The Governor should encourage non-governmental organizations to complete additional research focused on barriers and solutions to improving quality of end-of-life care in Pennsylvania.	Short Term (1-2 years)
156.	State policymakers from the Office of Health Care Reform, and the Departments of Health, Aging, and Public Welfare should collect, assess, and validate Pennsylvania data to determine the best way to optimize care for the last phase of life.	Intermediate (3-4 years)
157.	The Office of Health Care Reform, in conjunction with the Departments of Health, Aging, and Public Welfare, should work with CMS to implement a demonstration project studying the effect of risk-adjusted payments to Medicare and Medicaid managed care plans for patients with life-limiting, eventually fatal chronic illnesses in an effort to encourage continuity across time and health care delivery settings, including home-based care.	Intermediate (3-4 years)
158.	The Office of Health Care Reform, in conjunction with the Departments of Health, Aging, and Public Welfare, should work with the PA Hospice Network, payors, and the legislature to implement a demonstration project using an outlier formula for high-cost hospice patients.	Intermediate (3-4 years)

NUMBER	RECOMMENDATION	TIMELINE
159.	The Office of Health Care Reform should convene the Pennsylvania Health Care Cost Containment Council (PHC4) and the Task Force on Quality at the End of Life to design additional demonstration projects aimed at improving quality at the end of life and should administer competitive contracts to organizations interested in implementing these new models of care.	Intermediate (3-4 years)
160.	The Department of Insurance should evaluate the potential impact on overall health care costs and premium costs of a state mandate that private health insurers cover hospice and palliative care services as part of the basic benefit package using simulations based upon data from insurers currently covering and not covering these services.	Intermediate (3-4 years)

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Without the diligence, research, expertise, and dedication of the following individuals, this report would not be possible. We are grateful for their contributions.

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