

Hearing before the Pennsylvania House of Representatives
Committee on Aging and Older Adult Services:

Improving End of life Experiences for Older Pennsylvanians
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Chair Mundy and Chair Hennessey, honorable members of the Committee, good morning. Thank you for the opportunity to speak with you today about a matter that is extremely personal to each person in the Commonwealth – the quality of one’s life during its final stages. This topic is something that we too often ignore; no one wants to plan for and make difficult decisions about the period of time as we approach death. We plan for the quality of lives in so many ways but we often do not plan for the quality of our lives just before we die. This is a time when we need to have the option of being as well and comfortable as possible. It should be a time of dignity, but often it is instead a time when we are most dependent of others to make decisions that impact our quality of life. End of life care should be about choice that permits the consumer to have options that include both palliative and curative care and give them the optimal quality of death.

In 2002, the Robert Wood Johnson Foundation released a study entitled, “A Report on Dying in America Today.” It rated the states on eight key elements:

- advance-directive laws
- portion of deaths that occur at home
- rate and duration of hospice use
- access to hospice end of life care
- intensive care unit stays at end of life
- pain among nursing home residents
- state pain management policies
- number of doctors and nurses certified in palliative care

Pennsylvania’s average score in these areas was a “D.” The use of hospice was low, less than one quarter of all Pennsylvanians died at home, few hospitals offered palliative care and an inadequate number of physicians and nurses were certified in palliative care. The only area Pennsylvania received an above average grade was a “B” for the strength of our state pain policies.

In 2005, Governor Rendell appointed a statewide *Task Force for Quality at the End of Life*, under the leadership of the Pennsylvania Department of Aging. The Task Force issued a background paper outlining the issues and challenges related to end of life care for our state. An *End of Life Summit*, held in June of 2005, produced recommendations related to:

- ways to improve palliative care
- increasing palliative care specialists in health care facilities
- financing end of life care; coordination of care
- professional education; research needed
- and the needs of special populations, including people with disabilities, people in rural areas and older adults

In January of 2007, Governor Rendell issued the Prescription for Pennsylvania, a comprehensive blueprint for improving access, quality and affordability of health care. Among the initiatives outlined in Governor Rendell's "Rx for Pa" healthcare plan was a focus on quality at the end of life. Shortly after, the Department of Aging unveiled a series of policy recommendations designed to improve the quality of life for seriously ill and dying Pennsylvanians, their families and caregivers. The recommendations were contained in a report to Governor Rendell by the Task Force

Priority recommendations of the Task Force included the following:

- adhering to quality standards
- designing and implementing demonstration projects
- documenting treatment preferences
- improving education through licensing/accrediting/regulatory bodies and professional organizations
- engaging underserved communities
- raising public awareness

I am pleased to report that our Department, along with other key state agencies and the Governor's Office of Health Care Reform has made progress in these areas. In November 2006, Governor Rendell signed into law Act 169 which, among other things, established the Life Sustaining Wishes Advisory Committee tasked to provide recommendation to the Secretary of Health on a uniform physician's order related to life sustaining treatment. The Governor's Office of Health Care Reform through the Allegheny County Department of Aging commissioned the University of Pittsburgh, Graduate School of Public Health to prepare a report documenting palliative care services in Pennsylvania and recommendations for an improved service delivery model. The Pennsylvania Department of Aging has been working in partnership with Allegheny County Department of Aging to produce a set of videos entitled "Take Charge of Your Life" designed to encourage public discourse on the topic of end of life decision-making. The videos address advance planning, caregiving, hospice and palliative care, and pain management.

We have been working with hospice providers and Area Agencies on Aging (AAA) and other waiver providers to provide a more comprehensive approach to how home- and community- based long-term living services and hospice services are provided. We aim to comprehensively wrap them around each other, eliminating duplication of costs, so that it is a shared responsibility for both Medicare and Medicaid. This will not only improve efficiency of services but will also increase quality and prevent recipients and families from being passed between two systems. We are currently drafting a formal policy to outline the relationship between hospice and MA home and community-based waiver services. In November 2008 a memo was released to the Area Agency on Aging network in regards to coordinating hospice and waiver services. The memo clarified that individuals and their families should not be required to choose between two service systems that provide distinctly different yet equally important services. Based on a clarification statement from the Centers for Medicare and Medicaid Services released in December of 2008, a person who has "elected hospice

benefits and who also qualifies for the state's home and community based waiver program may utilize the benefits from both programs simultaneously."

Our memo identified that AAA care managers have the responsibility to collaborate with the hospice provider to ensure the services are appropriate to meet the needs of the individual and are person-centered. Waiver participants should be provided with as much information as possible prior to the election of the hospice benefit or enrollment in waiver. The hospice provider cares for the terminal illness and the waiver provider cares for the non-terminal conditions. The care manager will coordinate with the hospice provider those services not duplicative of hospice services that are necessary to meet the consumer's needs. Both agencies are responsible to inform the other of changes in the services provided. In supporting this type of coordination, we not only remain committed to a person-centered approach of service delivery, but we reduce costs associated with other healthcare settings.

In talking about hospice care, it is important to note that a key distinction of a quality end of life experience is a focus on palliative care, rather than a focus on treatment of disease. Soon a report will be released that lays out specific recommendations for an effective palliative care model in Pennsylvania. Medical dictionaries define palliative care as care that affords relief, but not cure. Curative care, on the other hand, is care that tends to overcome disease, and promote recovery. Many people erroneously equate palliative care only with hospice care. While hospice always provides palliative care, palliative care can be provided in other settings, can be long- or short- term, and can be combined with curative care or not.

Over the past century, our patterns of illness have changed. Previously, we primarily had acute conditions that resulted in relatively quick death. Today, due in large part to improved medical technology, many diseases – Chronic Obstructive Pulmonary Disease (COPD), diabetes, heart disease, cancer, and disabilities – cerebral palsy, spinal cord injury, spina bifida – are no longer an immediate death sentence and often are treatable for years. While medical technology has allowed for longer lives, which ultimately results in more chronic health conditions, our health care system remains focused primarily on curative care. Our current health care system is poorly prepared to provide comprehensive, coordinated care for those with chronic conditions, especially for those near the end of life.

As a result of the curative care approach of our health care system, costly measures to extend life are too often taken at the expense of quality of life. Palliative care has emerged as a potential solution that provides care from diagnosis to death, reduces pain and suffering, and coordinates care transitions, while possibly reducing emergency room visits, hospital stays, readmissions, and improving patient and family quality of life. Comprehensive palliative care addresses not only physical comfort but emotional and spiritual comfort. It not only involves a physician but an interdisciplinary team that provides support for the whole person. It is more than simply pain management. When palliative care is available and chosen, it has been shown to increase

patient satisfaction, increase the proportion of patients dying at home rather than in the hospital, result in fewer visits to the emergency room and reduced inpatient admissions.

From a public policy perspective, we have a responsibility to remove the barriers to palliative care. This hearing is an excellent step toward that end, as little public awareness about end of life issues is one of those barriers. Due to the discomfort that end of life issues create for individuals and their families, such topics are likely avoided and, in turn, options are rarely explored. It is not only the public that needs greater awareness of palliative care; utilization of palliative care is also severely limited by the lack of health professional awareness of services and assistance. Fewer than 40% of medical schools offer an elective course that deals with palliative care, and even fewer have made such a course a requirement. Treatment related to death and dying is often limited to a single lecture or to readings. Continuing Medical Education is not required of physicians either. This leaves the little knowledge that a doctor may have of palliative care outdated. An additional barrier is insufficient or limited health insurance coverage (outside of hospice coverage). Often insurance companies, Medicare and Medicaid do not cover a full continuum of palliative care. Instead, care at the end of life is paid for in a setting-based, acute incidence manner. It often fails to provide care coordination, home-based services, caregiver respite, and continuous pain management.

At end of life, trends show both nationally and in Pennsylvania that, while hospice is considered by many palliative care experts as the best treatment in terms of both quality and cost-effectiveness, more people are dying in nursing homes and hospitals than at home or in hospices. From a public policy perspective, we have the responsibility to change that.

While you and I are responsible for ensuring that Pennsylvanians have the best opportunity for a quality end of life experience, it is up to each person to make their own choices about what that experience means for them. This translates into making formal preparations for one's end of life and sharing those decisions with one's family. Making legal preparations for end of life decisions is one of the most important steps Pennsylvanians can take to ensure their final life stage is the way they envision it to be. Being well-prepared enables consumers and their family members to focus on quality of life rather than legal issues or disagreements over what they would have wanted. There are three basic documents an individual can prepare to ensure, as much as possible, that their wishes for treatment are followed: (1) Health Care Power of Attorney, (2) Living Will and (3) Out-of-Hospital Do Not Resuscitate (DNR) Order. A Health Care Power of Attorney and Living Will can be combined into one document known as an Advance Directive.

The Health Care Power of Attorney can be used to appoint someone to make certain medical decisions while one is incapacitated, but not necessarily at the end of life; Living Will provisions only go into effect if your attending physician certifies that you have an end-stage medical condition or you are permanently unconscious with no realistic hope of significant recovery.

Through a Living Will, one can describe what kind of treatment one wants – and does not want – at the end of life. Examples are CPR, dialysis, surgery, use of a ventilator, and medically-supplied nutrition and hydration (tube feeding). Consumers also name a health care agent to be empowered to advise medical staff if there are other decisions that need to be made about end of life treatment. Family members do not automatically have the authority to make decisions about end of life care. Putting one's wishes into a legal document and appointing family members or friends to make certain decisions on your behalf will help ensure that you retain as much control as possible over your medical care at the end of life. You should always have a discussion with the person you want to name to make health care decisions for you.

An out-of-hospital Do Not Resuscitate Order is an order signed by a physician, reflected on a bracelet, that instructs emergency medical technicians to withhold CPR in the event of respiratory or cardiac arrest in a terminally ill patient. The Department of Aging has a free brochure available that explains Advance Directives and includes a form that individuals can use. The form is taken from the provisions codified at 20 Pa. C.S. § 5601. This section of the law was significantly revised by Act 169 of 2006. Although an attorney is not required to fill out the form, consulting an attorney about end of life decisions is very helpful because they can help answer questions about the decisions to be made, and may be able to identify other legal needs such as estate planning or the need for a financial power of attorney.

In summary, we still have work to do to improve the quality of life at end of life in the Commonwealth. From fostering the availability of medical professionals trained on end of life care, expanding access to palliative care and hospice care and reviewing our advance directive laws, improving the quality of life at the close of the day is an important and honorable goal. Perhaps one of our most important tasks is to break the culture of silence that shrouds the issue. Today's hearing, along with the work that the Governor Rendell, the Governor's Office of Health Care Reform and the Department of Aging have done are steps in the right direction.