Pennsylvania Homecare Association

Statement of the Pennsylvania Homecare Association

In front of the

House Aging and Older Adult Services Committee
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Presented by

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Good morning and thank you Chairperson Mundy, Representative Hennessey and committee members. My name is Susan Gerhart. I am the National Director of Reimbursement and Outcomes for AseraCare Hospice, a past President of the Board of Directors of the Pennsylvania Homecare Association, member of the Lancaster County Office of Aging Advisory Council and was a member of the Task Force for Quality at the End-of-Life in Pennsylvania.

I commend the committee for holding this hearing to stimulate further discussion concerning end-of-life care experiences for Pennsylvanians and to explore what 'next steps' are necessary to improve end-of-life care in Pennsylvania.

AseraCare Hospice has 12 hospice agencies located throughout Pennsylvania that provide hospice care services for more than 800 people and their families on any given day. We take great pride in our family-centered approach, which ensures that the needs and wishes of both our patients and their family members are met throughout the hospice experience.

Hubert H. Humphrey stated "It was once said that the moral test of Government is how that Government treats those who are in the dawn of life, the children; those who are in the twilight of life, the elderly; and those who are in the shadows of life, the sick, the needy and the handicapped."

That statement still resonates well today. The *Improving End-of-Life Experiences for Pennsylvanians* report notes that "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...legislators, government officials, medical professionals, educators, activists and citizens." But little progress has been made since this report was released in 2006 as families seeking and utilizing hospice and end-of-life services in Pennsylvania still face daunting challenges in accessing these services. Hospice use remains low and less than a quarter of Pennsylvania residents die at home, even though they say that's where they prefer to spend their remaining days.

What is Hospice, Palliative Care and End-of-Life Care?

Let me begin by taking a moment to define some of the basic concepts.
The aim of hospice care is to provide the best possible quality of life, and to relieve pain and other symptoms at a time when the underlying disease can no longer be treated or cured and if the disease runs its normal course, the person's life prognosis is 6 months or less.

Palliative care improves the quality of life of patients and their families facing life-threatening illness. Particular attention is given to the prevention, assessment, and treatment of pain and other symptoms, and to the provision of psychological, emotional and spiritual support. Palliative care can be provided at the same time as life-prolonging and disease modifying therapies.

End-of-life care refers to the care provided across all health care settings to a person during the last part of their life, from the point at which it has become clear that the person is in a progressive state of decline.

Advances in modern technology and breakthroughs in modern medicine have allowed people to live longer, resulting in an increase in the number of people living with chronic illnesses. In addition, Pennsylvania today is faced with a growing elderly population. This population, people age 65 and older, comprises 15% of Pennsylvania's total population. Of this group, the number of people age 85 and over is projected to double to 7 million by 2020.

These facts help us shape our discussion here today: How can we, collectively, improve access to hospice, palliative and end-of-life care through a better coordination of services within the financial confines of today's Medicare and Medicaid budgets?

Today's Challenges

As a nation, Medicare currently spends 27% of its total dollars on people who are in the last year of life. About 70% of people who die each year are covered by Medicare, with about 13% also covered by Medicaid.
An independent study by Duke University in 2007 showed that patients receiving hospice care cost the Medicare program about $2,300 less per patient than those who did not receive hospice care, amounting to an annual savings of more than $2 billion.

These same kinds of savings could potentially be achieved in the Medicaid program through the better coordination of hospice services between various state Medicaid providers and programs. As the end-of-life report noted, care for people who are in the last phases of life is often delivered in a variety of health care settings, including acute care hospitals, skilled nursing facilities, inpatient hospice units and, where most people want to spend their last days if possible, at home.

One way to better coordinate this care is by allowing patients to access the Medicaid services necessary to allow them to remain at home. We support the draft bulletin, from July 2, 2009, that was created by the Office of Long-term Living. The bulletin clarifies the participation of consumers in Aging Waiver who are seeking hospice benefits. Currently, AAAs must contact the Office of Long-term Living to clarify questions or concerns regarding the addition of Waiver services. We strongly urge this bulletins speedy adoption.

Hospices, by definition, provide the core services of nursing, medical social services, counseling and aide services to a hospice patient and their family. The hospice benefit was designed to support caregivers of that hospice patient. It was not designed to be an all-encompassing benefit that provides continual caregiver services. This is an important distinction when it comes to discussing the role the Aging Waiver program has in conjunction with hospice care.

The role of hospice is to effectively help the patient manage the symptoms related to the terminal illness, including support of caregivers. This support of caregivers is offered by volunteers and, when appropriate, through short-term respite care. However, primary caregivers remain family and friends.

Yet many patients do not have access to an adequate support network in their homes. As a result many patients are left to spend their final days in a hospital or long-term care facility rather than at home because they cannot access adequate home and community-based services to allow them to remain at home.

Home and community-based services assist patients in being able to remain at home by providing them with assistance with activities of daily living. Many people are denied access to these services through the Aging Waiver because they are receiving hospice services. While we support the administration's efforts to ensure that Medicaid is the payer of last resort, it is important to realize that home and community-based services offered under the Aging Waiver program are not being used in place of hospice-covered care, but rather is a complement to the hospice benefit.

That is why we strongly support the report recommendation that the Departments of Aging and Public Welfare should work to reverse policies that restrict people on the Medicare hospice benefit from also receiving Aging Waiver services.

Under the new Conditions of Participation for Hospice providers, CMS allows for the coordination of care between these two programs.

Under Sections 418.76: Hospice aide and homemaker services
Services under the Medicaid personal care benefit may be used to the extent that the hospice would routinely use the services of a hospice patient's family in implementing a patient's plan of care.

The hospice must coordinate its hospice aide and homemaker services with the Medicaid personal care benefit to ensure the patient receives the hospice aide and homemaker services he or she needs.

The hospice benefit is not intended to replace a primary care giver. Rather, it should offer the expertise and support needed to live better at the end of life. This would also allow people to die at home, rather than in a more costly environment as a hospital or nursing home.

While we recognize that there are a myriad of other quality recommendations that will assist the state in advancing hospice care, the need to support patients and their families in the home is paramount. People should have a choice of where to die. That choice is a personal one and should be based on what is comfortable, not based on in which care setting is reimbursable.

Hospice and the Personal Care Home

Another challenge facing hospice patients is in the portability of advance directives, living wills and do-not-resuscitate (DNR) orders. Better education is needed for health care providers, families and consumers about these various methods for patients to express their wishes and the standard recognition of each of these documents throughout the health care system.
Despite having a DNR a hospice patient in a personal care home must have an ambulance called for them as described in the Licensing Measurement Instrument for the Personal Care Home Regulations, 55 Pa. Code, Chapter 2600.
As it is states, *if there is a DNR order and the resident requires emergency medical services, the home must contact emergency medical personnel. The home should inform the medical personnel of the resident's DNR order.*

Even with a DNR, the home must call emergency medical support (EMTs) in every incidence; they can withhold CPR if there is a DNR in place. The same rules apply for hospice residents as for any other circumstance.

A call to the hospice agency is also required; however, this does not take the place of the home's call to the EMTs. The hospice agency may choose to give alternate directions to the EMTs, but the home is not qualified or permitted to NOT call the EMTs

In accordance with state law 35 P.S. §450.507, a registered nurse (RN) is legally permitted to assess life signs and pronounce death. Therefore, if an RN or physician pronounces death of a resident, EMTs do not need to be called. This applies to hospice, as well as in all personal care homes.

This practice leads to a tremendous amount of confusion and anxiety for the patient and their families. Hospice personnel have been instructed to work directly with each EMT unit to create a process to address this issue on a patient-by-patient basis rather than having it addressed in the personal care home guidelines. This is another example where better coordination of care focused on the patient could help Pennsylvania reach its goal of better quality end-of-life care.

Thank you for this opportunity to share my insights on just a few of the opportunities available in Pennsylvania to better coordinate care between providers for the benefit of all Pennsylvanians. I would be happy to answer any questions you may have.