

Mr. Chairman, members of the Committee, ladies and gentlemen, it is a privilege to be here today.

My name is Linda Todd, and I am Director of Hospice of the Siouxland, located in Sioux City, Iowa. I also serve on the Board of Directors of the National Hospice and Palliative Care Organization and am testifying on its behalf today. The National Hospice and Palliative Care Organization is the largest nonprofit membership organization representing hospice and palliative care programs and professionals in the United States. The organization is committed to improving end of life care and expanding access to hospice care with the goal of profoundly enhancing quality of life for people dying in America and their loved ones. The National Hospice and Palliative Care Organization offers information on local hospice and palliative care programs across the country, operates a toll-free Helpline at (800) 658-8898, and maintains a website at **[www.nhpco.org](http://www.nhpco.org)**.

I am honored to have been asked to testify today about public educational efforts focused on improving end of life care, but first, I would like to address the delivery of such services in the setting that I know best. It's an approach to care that each year meets the needs of over 700,000 terminally ill Americans and their families. Of course, I am referring to hospice care.

The modern day American hospice movement began in 1971 in Connecticut. The first freestanding hospice in this nation was the Connecticut Hospice in New Haven and it was founded on the model of care best identified with Dame Cicely Saunders, MD, who opened her now famous Saint Christopher's Hospice in 1967 in Sydenham, England. Her center became the model for comprehensive whole person and family care at the end of life (i.e., spiritual, psychological and medical team-driven care of the terminally ill patient and his/her family).

While hospice began as a movement in this country, it was made part of the Medicare program in 1982. Since enactment, the Benefit has afforded millions of terminally ill Americans and their families an avenue toward a death with dignity.

Simply defined, hospice care focuses on whole person care, and is not, as too often is thought, just a place to die. Hospice embraces these principles:

- Supports and cares for persons in the last phases of incurable disease so that they may live as fully and as comfortably as possible;
- Recognizes dying as part of the normal process of living and focuses on maintaining the quality of remaining life;
- Exists in the hope and belief that through appropriate care, and the promotion of a caring community sensitive to their needs, patients and their families may be free to attain a degree of mental and spiritual preparation for death that is satisfactory to them; and,
- Offers palliative care to terminally ill people and their families without regard for age, gender, nationality, race, creed, sexual orientation, disability, diagnosis, availability of a primary caregiver, or ability to pay. (NHPCO Standards of Hospice Program of Care, 1993)

Far too many patients die without ever being referred for hospice care. This is often the result of an unawareness of hospice and palliative care programs by patients and their families. As we heard in the previous panel's testimony, this lack of knowledge or awareness of compassionate end of life care can lead to tragic and unnecessary pain and suffering - physical, emotional and spiritual -- for the patient and their families. That kind of suffering does not have to happen in Sioux City or anywhere else in the country.

There is a great deal of pride in the health care services that are offered in Sioux City, Iowa. We have a

trauma center, a burn unit, a regional cancer center, a heart program, a neonatal intensive care unit as well as a full array of healthcare services along the continuum of care. And yet, our health care system failed a patient and their family in the last months of her life---not because of our lack of expertise or technology, but rather because of the lack of recognition of their end of life care needs.

Shelly Twiford wanted to talk with me after the death of her mother. The overriding question was...How did the hospice nurse know, in a few minutes, her mother was dying and no one else within their health care system had told them her mother was terminal? As I listened to their story, I was overwhelmed with the experiences of this family. There seemed to be road blocks every step of the way. Reflecting on their situation, we could identify the need for pain and symptom management; personal care assistance; emotional and spiritual support, and financial assistance. We could sense the frustration and the chaos that this family experienced during the last months of her mother's life.

As a provider of hospice services for fifteen years, I knew in my heart that hospice care could have made a difference for Shelly's mother and her family. With the assistance of our interdisciplinary team, there could have been nursing visits that would have achieved pain and symptom management with the coordination of physicians. Home visits would have provided the necessary interventions that would have eliminated the need to transfer her mother to the emergency room because she was unable to urinate. There would have been a social worker that could have assisted the family with the emotional support -- understanding and encouraging them to share their fears and facilitating the discussion within their family to foster the relationships and quality of life, which promote personal closure within a family unit. A home health aide could have provided the personal care for her mother---and volunteers could have visited to provide relief for the husband. The team would have assisted the family in understanding of disease progression, what to expect, how to do home care management, instructions on who to call and when to call. The Medicare Hospice benefit would have paid for all of this, including the interdisciplinary team services, the medications, the medical equipment, the medical supplies, respite care, and even inpatient care, thus relieving the financial burden for the family. Treatment options could have been discussed with the patient and their family and then, with the hospice staff knowing their wishes, they would have been able to advocate for their needs as family members. Shelly's mother would have been able to remain in her home to die---the same place she had lived. And during bereavement, when they had lost the person they loved dearly---they would have the support to assist them with their grief, but also know there is a level of satisfaction and comfort from feeling like they had been able to respect and maintain her wishes--- rather than feeling like they, as a family, had failed.

This situation came at a time when, within our own hospice program, we were dealing with short-term referrals--- 28% of our patients were referred to hospice for seven days or less. My program is struggling financially and my staff is drained from frequent crisis management of the short-term patients and the frustrations that hospice care was not being utilized for the maximum benefit of these patients. As a hospice team, you can't get there fast enough because you know there is so much to accomplish and so little time. There are different situations and different families, but there is the same recurring theme. Health care providers do not recognize the needs of patients and families, and patients and families don't know who or how to ask for assistance.

What will change these situations? Whenever you ask the question, the answer always comes back to the same response --- education, education, education --- education for consumers, for health care professionals, and for physicians. Death is not failure, it is a part of life and we, as Americans, must embrace this thought and deal with the reality of death. Until we do, patients and their families will continue to suffer. Shelly's story is a powerful example of the need for change. That change needs to occur on a local level, as well as on a national level.

A local call to action developed in response to this situation. An end of life task force in Sioux City was

formed with representation from hospitals, nursing homes, community agencies, educators, consumers, clergy, lawyers and multicultural populations. Education and promotion of advance care planning have been the major thrust of our initiatives. Thus far, we have had three physicians in our community complete the EPIC program and have had monthly educational luncheons with family practice residents with an EPIC module as the agenda. We have initiated a major donor campaign of one million dollars to fund these educational efforts, as well as to develop a palliative care service that will provide consultation for pain and symptom management, and offer emotional and spiritual support for patients and their families much earlier in the disease process.

We are one community of many---and, tragically, there are far too many similar stories begging for change across the country. As a local provider, I do not have the resources or the ability to implement change as effectively as a national effort can provide.

Recent research by the National Hospice Foundation showed that Americans are more likely to talk to their children about safe sex and drugs than to their terminally ill parents about choices in care as they near life's final stages. According to this research, one in four citizens over the age of 45 say they would not bring up issues related to their parent's death - even if the parent had a terminal illness and had less than six months to live. One out of every two Americans say they would rely on family and friends to carry out their wishes, but 75 percent of these people have never taken the time to clearly articulate how they wish to be cared for during life's final journey.

There are nearly 40 million senior citizens in the United States, but in the next 30 years, that number is expected to double to 80 million as baby boomers reach age 65. Surprisingly, 90 percent of the respondents didn't realize that all inclusive hospice care is available to this aging population, as Medicare beneficiaries.

Once the subject of end of life care is broached, it is clear what we want. The NHF research indicates what people would choose when provided end of life care:

- Someone to be sure that the patient's wishes are enforced,
- Being able to choose the type of service they could receive,
- Emotional support for patient and family,
- Control of pain,
- Opportunity to get one's life in order,
- Spiritual support for patient and family,
- Care by a team of professionals,
- Being cared for in one's own home,
- Continuity of care, and
- Relief of burden on the family and friends.

In fact, these are the guiding tenets of hospice care.

The entire topic of how we want to be cared for when we are dying makes us uncomfortable, but we need to talk about it. Whether it is around the kitchen table or behind the witness table here in Congress, the American public needs to start a dialogue about how they want to be cared for at the end of life.

To facilitate these discussions about end of life care decisions and to raise public and health care sector awareness, the National Hospice Foundation has initiated a three year, multi-million dollar public engagement campaign. During its first year, campaign activity is focusing on four elements - public service announcements, online partnerships, medical education, and hospice story placement.

Public service announcements will heighten public awareness about hospice care at both national and local levels. The messages are aimed at prompting families to have these important conversations with their loved ones, before a health care crisis or tragedy force the issue upon them.

Within the context of the campaign, NHF will be pursuing on-line partnerships. Many more consumers now get medical information on the Internet - particularly women and baby boomers. There are far too many health-dot-coms with no hospice information. The campaign is designed to change that.

Another element of the public engagement campaign is medical education. It is not only consumers we have to educate about hospice care. Physician referral is critical to hospice access. Doctors are trained and educated to keep people alive as long as possible. Many are reluctant to refer patients to hospice. This effort will help hospice programs expand outreach, and be seen as problem solvers by physicians and team with them earlier in the disease process.

An additional component of the public engagement campaign focuses on national and local news coverage of hospice and the need for quality end of life care. This press coverage will promote a national dialogue on the critical needs of our most vulnerable population, the terminally ill and their families. In turn, these conversations will build an ever-increasing customer demand for responsive and compassionate end of life care.

Congress recognized the need for such care in 1982 when it enacted the Medicare Hospice Benefit to provide compassionate and specialized care for the dying. While millions of terminally ill older Americans and their families have had the opportunity to experience more comfortable and dignified deaths, the reimbursement rate has not kept pace with the changes in end of life care -- especially due to increasing costs of prescription drugs and outpatient therapies, as well as decreasing lengths of service. Medicare Hospice Benefit reimbursement rates need to be increased if hospice programs are to continue to provide high quality care and related services that our nation's most vulnerable population needs and deserves.

Once a patient chooses hospice care, he or she is afforded the per diem reimbursement as the only Medicare payment for all costs related to the terminal illness, including physicians' oversight services, nursing care, counseling, spiritual support, bereavement counseling, medical appliances, drugs, home health aides, homemaker services, physical and occupational therapies, dietary advice, and volunteer assistance. An interdisciplinary team provides medical, social, psychological, emotional and spiritual services to the hospice patients and their loved ones.

In 1982, when hospice care was added as a Medicare benefit, the routine home care rate was set at \$41.46 per day. When the benefit was established, the reimbursement rate did not include an annual inflationary update. Rather, Congress provided specific rate increases and later tied the hospice reimbursement rate to the hospital market basket to provide for inflation. Unfortunately, the rate has not kept pace with the growing cost of delivering care to terminally ill Medicare beneficiaries. The fiscal year 2000 routine home care rate, at which more than 95% of all Medicare hospice patients are billed, is \$98.96.

Unfortunately, the current reimbursement rate does not begin to cover the expenses incurred in delivering compassionate and specialized care to dying Americans. An interim report of an ongoing hospice cost study by Milliman & Robertson (M&R) states, *"the trend is clear that Medicare hospice per diem payments do not cover the costs of hospice care and result in significant financial losses to hospice programs throughout the country."* M&R notes several other factors driving the losses that hospices are experiencing today.

According to the M&R study, *"new technology, including breakthrough therapies and prescription drugs, has increased hospice costs far beyond Medicare's annual market basket update. For example, when Medicare set hospice payments in the 1980s, prescription drugs for hospice patients represented about \$1 of the per diem reimbursement rate. M&R noted that these costs increased to approximately \$16 per day by the late 1990s (an increase of about 1,500%)."* Drug costs have skyrocketed, making pain relief and symptom management, cornerstones of hospice care, much more expensive. Many of the most effective and widely used drugs for relief of cancer patients' discomfort are shockingly expensive. Duragesic, one of the most commonly used pain relievers for cancer patients, can cost up to \$36 per dose. Zofran, an effective anti-nausea drug, costs almost \$100 per day - exceeding the entire routine home care rate paid by Medicare to the hospice provider.

But escalating drug costs are not the only problem facing hospices.

For a variety of reasons, more and more patients are being admitted to hospice programs very late in their illness, when they require a greater intensity and variety of services. Their hospice care needs, including pain and symptom management and personal support, are often the greatest in the first few days following admission and in the final days and hours before death.

The Medicare Hospice Benefit was designed to balance the high costs associated with admission and the period immediately preceding death with the somewhat lower costs associated with periods of non-crisis care. However, the median length of service for hospice patients has fallen rapidly in recent years leaving fewer "non-crisis" days. The very short lengths of service and advances in clinical practices, both significant cost factors, were not anticipated at the time the original rate structure was formulated. These added financial pressures are having a devastating impact on hospices.

In the longer-term, Congress needs to undertake a review of the assumptions under which hospice reimbursements are made. New drug treatment modalities and types of medications have come to establish new areas of medical practice, and we need to have them available to the hospice practitioner and other health professionals. We in hospice know how to alleviate pain and control symptoms. But, far too often, the skyrocketing cost of such treatments force us to seek other less expensive and perhaps less effective alternatives. In fact, the vast majority of the NHPCO's members resort to public fundraising to supplement their operational and capital costs. Within the context of the Medicare Hospice Benefit, we need a dramatic increase in our reimbursement rates and elimination of the reductions in the inflationary adjustment to our rates imposed by the Balanced Budget Amendments of 1997 (BBA). We need these changes now.

Routine regulatory reviews and investigations are having a substantial, and presumably unintended, adverse impact on end of life care and access to hospice. Such reviews should be undertaken with the goal of assuring quality patient care and compliance to the intent of the regulations. The National Hospice and Palliative Care Organization strongly supports that goal. Unfortunately, many of the regulatory actions deal with technical interpretations of the regulations and they are neither focused on nor related to good patient care. The investigations, on the other hand, have the unintended effect of creating a chilling environment for attending physicians and hospice providers, fearful of government review and possible prosecution.

According to the Medicare Payment Advisory Commission, "[t]he gap between the care now given to dying beneficiaries and ideal care is wider than in probably any other area of medicine... closing this gap should be one of the highest priorities of the Medicare program."

By adopting the Medicare Hospice Benefit in 1982, Congress took an important step in changing a

deeply embedded aspect of our culture, one that denies the inevitability of death and ignores the value of the end of life. We continue to believe today, that hospice care is our best response to caring for people at the end of life.

Yet, there are any numbers of obstacles to ensuring access to hospice care for individuals in this country. In fact, we are witnessing an alarming decline in the lengths of service for hospice patients, which is turning hospice into a "brink of death" benefit. The National Hospice and Palliative Care Organization's data show that the number of hospice patients has steadily increased, totaling over 700,000 individuals last year. In 1998, their median length of service fell to just 25 days, which represents a 26% decline since 1992. This means that over one half of all hospice patients - 50% of men, women and children in hospice care -- die within one month of admission. This is happening at a time when access to hospice care should be deepening and broadening, not contracting.

We all agree that eliminating fraud and abuse is critically important to preserving and protecting the Medicare Trust Fund. It is becoming increasingly clear, however, that anti-fraud efforts, which have focused attention on the very small percentage of patients who have outlived their six-month prognosis, have created an environment of fear among referring physicians and hospices that has limited access to hospice care. The impact on families and patients who are appropriate for hospice care, but never receive it because of the government's approach, is devastating.

When designing the Medicare Hospice Benefit, Congress recognized that predicting when death will occur is not an exact science. Even the Office of Inspector General (OIG), after its exhaustive three-year audit and investigation of the hospice provider community, concluded that "[o]verall, the Medicare hospice program seems to be working as intended." But the cloud of concern raised by these efforts continues to impede appropriate access to hospice care for the terminally ill.

In its 1997 report, *"Approaching Death, Improving Care at the End of Life,"* the Institute of Medicine warned:

"Although hospices should not be immune from investigations of possible fraud or abuse, the committee urges regulators to exercise extreme caution in interpreting hospice stays that exceed six months as evidence of anything other than the consequence of prognostic uncertainty. To do otherwise would inappropriately penalize hospices and would threaten the trust that dying patients need to have in those who care for them. It might also discourage more timely admission to hospice of patients now referred only a few days before death, after important opportunities for physical, psychological, spiritual and practical support have already been missed."

Another example of the "chilling effect" is legislation, S. 1451, the Medicare Waste Tax Reduction Act, that would provide for civil monetary penalties, and would invite government scrutiny of physicians who refer patients to hospices if those patients do not die within the six-month prognosis. Potential cases of fraud and abuse in hospice programs are already sufficiently covered under existing law and we support their enforcement. The overall effect of these policies and activities has created a climate in which hospices and, most importantly, attending physicians fear that unless they can predict with certainty that a patient will live no longer than six months, they will be subject to increased government scrutiny and possible sanctions for hospice admissions or referrals. The end result of this atmosphere usually relegates patients to continued hospitalization at far greater costs to the Medicare Trust Fund. But a referral to hospice can save Medicare money. A Lewin (1995) study cited savings of \$1.52 to the Medicare program for each \$1.00 spent on hospice.

These actions, taken together, have created a negative environment for hospice care, which has now

spilled over into the routine Medicare certification survey process. The perspective of many of our provider members is that minor deficiencies in paperwork and documentation processes are being elevated to more serious 'condition level' violations during exhaustive and costly surveys. These are then used as the reason to decertify hospice programs of long standing tenure with otherwise good records for compliance and quality of care to patients. For example, one program was cited for being out of compliance with a condition of participation when its nurse made four visits to a home instead of the two or three called for in the plan of care.

In another instance, a program was cited because there was no physician involvement in a patient's revocation of the hospice benefit. The patient alone has the right, at any time, and for any or no reason, to revoke the hospice benefit. There is no legal or regulatory requirement whatsoever that mandates that either an attending physician or the hospice's medical director be involved in the revocation process.

Mainly as a result of disputes over technical interpretations and the government's tactics, the impact on patients and their families has been severe and extremely disruptive -- at a most vulnerable time of life. While hospice programs have suffered huge costs and loss in admissions, patients and families have suffered more in terms of dislocations and access to care, not to mention caregivers who have lost jobs or been relocated to other hospices.

There is no better success story in Medicare than the Hospice Benefit. It is serving over 700,000 patients and their families annually with a well structured, comprehensive and cost-effective benefit. Yet, the combination of policies and actions has conspired to impair access to hospice care. We need help to reverse this cycle and reduce the growing climate of fear that now engulfs physicians and hospices as they struggle to admit and care for our most vulnerable citizens.

We applaud and support the efforts to eliminate Medicare fraud. However, in the spirit of the Institute of Medicine's warnings and in the face of unquestionable suffering and need, it is troubling that the unintended effects of these actions tend to limit timely access to hospice care.

Hospices need a supportive environment that focuses on issues that matter to the quality of care in hospice programs. Terminally ill citizens and their families need a strong, clear and consistent message that encourages the earliest consideration of hospice care within the dying process and that ensures access to this specialized form of care becomes more readily available to our most vulnerable population.

Apart from the hospice setting, we need to focus attention on the inadequacy of pain management for chronically and terminally ill patients. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) on how persons died in hospitals reported inadequate pain management and inattention to a patient's express wishes in their choice of care as common. Clearly, these and other issues, including a self-determined life closure, a safe and comfortable dying and appropriate and effective bereavement need to be addressed if we are improve the process of dying in America.

In providing whole-person care, health care professionals must take the time, even in the present managed care environment, to listen attentively, be present and enter into dialogue with their patients. These same health care professionals must also understand and practice state-of-the-art pain and symptom management (such as those developed and honed over the past 25 years by hospice and palliative care programs). It is within this context that the government needs to devote additional resources to further develop and advance the scientific understanding of pain and symptom management and make the information widely available to physicians, pharmacists, hospitals, research institutions,

local governments, community groups and the general public.

Far too many medical education institutions are deficient in addressing suffering and palliative medicine as an integral part of their curricula. Established medical practitioners (other than hospice professionals) often lack an aggressive commitment to alleviate the distress and suffering of the dying. Concern about the use of opiates abounds. Palliative care physicians working with hospice-trained nurses and others can, in virtually all patients, control the physical distress of dying. If patients are provided timely and appropriate care, they will have been receiving opiates or other medications, if needed, for some time prior to their death. In that situation, escalation of medications if required to manage severe pain, is well tolerated and will not, per se, hasten death, but will allow a more peaceful and dignified dying.

Our health professions' schools need additional resources to develop and implement programs to provide ongoing education and training to their students in all phases of palliative care. Once these professionals are armed with the knowledge of new and constantly updated pain and symptom management techniques, they need to be assured that their aggressive treatment of pain and symptom management will not be hindered by outdated concepts or misguided legal review. As practicing health care providers, we need access to readily available and state-of-the-art guidelines for the treatment of pain.

Effective pain and symptom management needs to be recognized as a core service of our health care community. Longer-term solutions involve exploring the legal and regulatory barriers to pain management, the level of competence in treating pain by physicians around the country and how the reimbursement policies of both the Federal health programs and private health insurers affect pain management.

Hospice programs and organizations have a responsibility to educate patients, medical students, residents, health care professionals, managed care systems, our communities and our congressional leaders about quality end-of-life care and for whom and when it is appropriate.

The Medicare Hospice Benefit has served as a wonderful basis for paying for hospice care. Its reimbursement rates need to be dramatically increased in order to bring it current with new technologies and treatment modalities. However, as our knowledge and experiences have grown, we need to think about how we can better extend hospice and palliative care to children, minorities, and persons with advanced chronic, non-curable diseases to ensure universal and timely access to hospice services when desired and appropriate, not just in the last few days or months of life.

This list of recommendations is certainly not all-inclusive. So much more can be done. But understanding human suffering and how to help patients and their families facing end-of-life problems and issues are essential. By enhancing the educational process and focusing public attention on end-of-life issues, we will increase the awareness of when patients will most benefit from non-curative, supportive hospice and palliative care, thus providing timely hospice referrals and understanding where such care fits in the continuum of medical care.

It is time to re-examine how we care for our most vulnerable citizens, the terminally ill and their families, so they might enjoy living to the fullest -- even as they approach death.

Thank you.