

Witness:

Dr. J. Donald Schumacher

National Hospice and Palliative Care Association, Alexandria, VA

President and CEO

Testimony

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

My name is J. Donald Schumacher, and I am President and CEO 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 and oldest nonprofit leadership organization representing hospice and palliative care programs and professionals in the United States. Our 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.

Talking about death makes most people uncomfortable. However, we have a responsibility to our families and loved ones to make our end-of-life wishes known. 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. In response to recent headlines, tens of thousands, if not millions, of people have requested information on advance care planning and hopefully, those personal conversations have started.

It is an indisputable fact that all of us will die. Yet, until the past several weeks, Americans have for the most part been unwilling to plan for this eventuality. In fact, most families spend more time planning for their annual summer vacation than they do for a health care emergency.

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.

This year, the National Hospice and Palliative Care Organization launched Caring Connections, a consumer education initiative funded with support from the Robert Wood Johnson Foundation. Caring Connections provides free resources about advance care

planning; including state-specific advance directives to help families better understand options for care at the end of life. The Caring Connections Web site, www.caringinfo.org also provides information on care giving, pain, hospice, financial issues and grief. So far this year, Caring Connections has disseminated advance directives and resources to more than 15,000 consumers.

In a single day, the National Hospice and Palliative Care Organization's Caring Connections HelpLine staff fielded more than 900 phone calls and processed more than 2 000 emails from people across the country requesting copies of state-specific advance directives. But, requesting a form is not enough. You must complete the form and take additional steps. These include giving the completed form to your doctor, family, and friends, and then use the form to talk to people about these issues and your wishes at the end-of-life.

It is important to note that advance directives are not only focused on what treatments you do not want. They are equally applicable and viable to indicate all of the treatments that you do want. This information gets lost in the information about their utility. Whether you want your health care providers to try every possible life-prolonging treatment until the moment you die, or to solely focus on providing comfort care at the end-of-life, you still need to document and talk about your wishes.

Through a Robert Wood Johnson Foundation grant, NHPCO is launching a national consumer education and engagement campaign this month called "It's About How You LIVE." The LIVE acronym is a call to action and empowerment for consumers:

- Learn about options for end-of-life services and care
- Implement plans to ensure wishes are honored
- Voice decisions and plans to family, friends, spiritual care and health care providers
- Engage in personal, community or national efforts to improve end-of-life care

This national effort is the first step for our organization in implementing a far-reaching consumer information campaign. We are seeking national, state, and community partners to join our efforts in promoting these important messages to people across the country.

Congress also has the opportunity to take the next step by approving legislation that will highlight and strengthen advance directives. S. 347, The Advance Directives Improvement and Education Act, introduced by a bipartisan group of Senators, is a bill that NHPCO has supported for a number of years in previous Congresses and we have recently reiterated our support for the bills' provisions.

The Advance Directives Improvement and Education Act encourages all Medicare beneficiaries to prepare advance directives by providing a free physician office visit for the purpose of discussing end-of-life care choices and other issues around medical decision-making in a time of incapacitation. Physicians would be reimbursed for spending time with their patients to help them understand situations in which an advance directive would be useful, medical options, the Medicare Hospice Benefit, and other

concerns. The conversation would also enable physicians to learn about their patients' wishes, fears, religious beliefs, and life experiences that might influence their medical care wishes. These are important aspects of a physician-patient relationship that are too often unaddressed.

Another part of the bill would provide funds for the Department of Health and Human Services to conduct a public education campaign to raise awareness of the importance of planning for care near the end of life. This campaign would explain what advance directives are, where they are available, what questions need to be asked and answered, and what to do with the executed documents. HHS, directly or through grants, would also establish an information clearinghouse where consumers could receive state-specific information and consumer-friendly documents and publications.

State-specific information is needed because in addition to the federal Patients Self-Determination Act passed in 1990, most states have enacted advance directive laws. Because the state laws differ, some states may be reluctant to honor advance directives that were executed in another state. The bill contains language that would make all advance directives "portable," that is, useful from one state to another. As long as the documents were lawfully executed in the state of origin, they must be accepted and honored in the state in which they are presented, unless doing so would violate state law.

All of the provisions in the Advance Directives Improvement and Education Act of 2005 are there for one reason: to increase the number of people in the United States who have advance directives, who have discussed their wishes with their physicians and families, and who have given copies of the directives to their loved ones, health care providers, and legal representatives.

I am honored to have been asked to testify today about public educational efforts focused on decision making at the end of life, but, I would also 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 one million 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.

Hospice is not "a place." It is an approach to end-of-life care focused on pain relief and

symptom management, and hospice care is offered primarily in a patient's home. It can also be provided in a nursing home, assisted living facility, a hospital, or in a hospice inpatient facility.

No one is ever forced to use hospice care. People either choose hospice care themselves or their health care surrogate, designated as responsible for their best interest, makes the decision. Normally, a physician outside of hospice is involved in the decision and he or she must certify that the patient's illness is terminal and that they have a limited life expectancy.

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 patients and families being unaware of hospice and palliative care programs available to them. This lack of consumer education regarding 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 your city or anywhere else in the country.

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 to the NHF study 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.

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 maintained 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 2005 routine home care rate, at which more than 95% of all Medicare hospice patients are billed, is \$122.

Unfortunately, the current reimbursement rate does not begin to cover all of the expenses incurred in delivering compassionate and specialized care to dying Americans. A 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 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 its May 2002 Report to Congress, MedPAC recommended that the Secretary of Health and Human Services study ways to develop a high-cost outlier policy to address these issues.

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 one million individuals last year. In 2003, their median length of service fell to just 22 days, which represents a 24% decline since 1995.

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.

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.”

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.

We are awaiting the release of a cost efficiency study conducted at Duke University that was funded through a grant by the Robert Wood Johnson Foundation that we hope will also demonstrate substantial cost savings for the Medicare program while providing high quality end-of-life care.

There is no better success story in Medicare than the Hospice Benefit. It is serving over one million 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 concern 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 may 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, 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 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.

As you may know, authority for the Health Professions programs expired on September 30, 2002. As this committee turns its attention to the reauthorization of these programs, we encourage you to address the issues we are discussing today by establishing Hospice & Palliative Care Academic Career Awards (PACA) modeled after the geriatric awards (currently receiving \$6 million). This is an emerging field in medical training. The proposed awards would provide funds for junior faculty and require they spend at least 75% of their time training interdisciplinary teams of health care professionals in hospice and palliative medicine.

One valuable lesson in the health care cases watched by the world over the past few weeks is how important expert, sensitive, compassionate medical care is at the end of life. Many hospices and hospitals are interested in hiring physicians with training in this field, but there are very few training programs available. A crucial step forward would be the support of young faculty in palliative medicine to ensure that the nation's medical schools are training future generations of physicians how to properly care for patients with advanced illness, as well as their families.

In order to prevent distressing struggles with health care choices, it is critically important that physicians be trained how to help patients and families come to terms with their conditions and make the difficult choices that are so common, especially near the end of life. The legislation introduced last Congress by Senator Wyden; the "Palliative Care Training Act" will do this by encouraging the hiring and training of Palliative Medicine experts, who are skilled in helping patients and families through this challenging time. This legislation is a positive, forward looking response to the tragic struggle we have all witnessed.

Trained palliative care specialists can upgrade the skills of all the physicians they work with, and improve the "standard of care" of patients with life-limiting diseases. As we confront the complex issues of how to pay for the care of our aging population, palliative care is one of the few areas in which the best care is often less expensive, because it can be done at home. Hospitals are finding it financially advantageous to pay the salaries of such specialists because the patients get more comfortable quickly, families feel more able to cope, and the discharge home happens sooner, reducing the costs significantly. Health care dollars would go much farther if they were used to provide expert palliative care at home or in a hospice inpatient unit, rather than in a hospital. By adding significantly to the number of teachers in this new field, this act could generate substantial savings, while relieving the suffering of distressed families. We urge your consideration of this legislation as you pursue the Health Professions Reauthorization.

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 grow, 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. Understanding human suffering and how to help patients and their families face the end-of-life with dignity is 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.