

Testimony of Frances Hoffman

Mr. Chairman, ladies and gentlemen, thank you for the opportunity to speak with you today.

My name is Frances Hoffman. I am the Executive Director of Hospice of North Iowa which serves sixteen counties in northern Iowa. Last year we served 800 patients and their families during a critical time in their lives.

When the National Hospice Foundation researched what people in the United States want at the end of their lives it found that they want the following:

- Someone to be sure that their wishes are enforced
- Ability to choose the type of services they want
- Emotional support for themselves and their families
- Control of pain
- Opportunity to get their lives in order
- Spiritual support for themselves and their families
- Care by a team of professionals
- Care in their own homes
- Continuity of care
- Relief of the burden on their families and friends

All of these elements are available through hospice care. If the Medicare Hospice Benefit is so wonderful, why am I here testifying? There are significant barriers to providing hospice care to all who might benefit from it.

The first barrier is the requirement that all hospice patients must have a six-month prognosis from their physician. As Dr. Christakis so eloquently presents in Death Foretold, his study on prognosis in medical care, physicians have a great deal of difficulty in foretelling how long a patient may have to live. In his work, Dr. Christakis cites a study where he "found that only 20 percent of predictions were 'accurate,'Of the remaining 80 percent of predictions, most (63 percent of the total) were overestimates of survival..." The result of this overoptimistic view of their patients' life span is that physicians refer to hospice very late in an illness--when it is abundantly apparent that a patient's death is near. Hospice services were designed to help a patient through the last six months of life. The reimbursement structure was designed based on this precept as well. When patients come to hospice a few weeks or even days before they die, the benefit they and their families receive is significantly reduced. I would encourage you to consider demonstration projects to test alternative eligibility criteria to the six-month rule.

A second barrier is the short length of stay of many hospice patients. A hospice patient in my hospice now will average 39.5 days of care. Over 30 percent of our patients are with us less than a week. Let me

give you two examples of patients to give you an idea of the difference in what we can provide in care if we have the time to do it. These are actual patients of Hospice of North Iowa, although I have changed their names to protect their confidentiality.

"Larry" was an 85-year-old man with renal insufficiency, hypothyroidism, Alzheimers, diabetes, pneumonia, and a feeding tube. He was with us for two days. He lived in a nursing home and was referred to hospice as he was actively dying. The hospice nurse provided medications to ease the symptoms of dying for Larry and explained the dying process to Larry's family. The hospice social worker talked with the family about grief issues as Larry died. The hospice bereavement social worker provided follow up with the family for 12 months after Larry's death.

"Virginia" was with us for six months. She had ovarian cancer with metastases, a colostomy, a feeding tube, a central line, a large abdominal wound from surgery, an ileostomy, and a rash over much of her torso. She was an 82-year-old grandmother who had always been the strength of her family. Her husband and daughters were having a very difficult time accepting her critical illness. Virginia was admitted to hospice in the spring. She came to hospice from the hospital where she had had abdominal surgery. It appeared when she was admitted that her death was imminent. Virginia was taken to her home where a hospice nurse provided medications, wound dressings, and equipment to help her deal with her colostomy. A hospice home care aide provided baths and other care five days per week. The hospice social worker and chaplain worked with the family to help them adjust to Virginia's illness and to cope with the anxiety of caring for her at home. Virginia rallied after her first four days in hospice and she was able to go out for some drives with her husband during the summer months. The social worker worked with Virginia to help her address self-image issues that she had as a result of the many wounds and tubes she now had to deal with in addition to the loss of her hair. Virginia's husband and daughters were dealing with a great deal of anger at losing their support and "best friend". The social worker held several family conferences to help them work through these feelings. In late fall, Virginia began to decline rapidly. The hospice nurse arranged for oxygen for her and increased her pain medications. A hospital bed, trapeze grab bar for over the bed and an overbed table were provided. Virginia developed shingles and the hospice nurse provided medication to soothe this condition. After several weeks of increasing decline and weakness, Virginia died very quietly at home. Her family had come to accept her illness and death. The bereavement social worker from hospice continues to follow up with the family as they grieve the loss of the woman whom they had relied on to support them through the years.

Clearly, the quality of service we can provide is dramatically improved when we have some time with a patient. Our financial picture is also greatly affected when our patients are with us only a matter of days. The Medicare Hospice Benefit was designed to balance the high costs of admission and the period immediately preceding death with the somewhat lower costs of caring for patients during non-crisis times. With very short lengths of stay, there are few non-crisis days any more. This results in growing financial pressures that are having a devastating effect on hospices.

When the Hospice Medicare Benefit was implemented in 1982, the routine home care rate was set at \$41.46 per day. The rate did not include an annual inflationary update. Instead, Congress provided specific rate increases and later tied the hospice reimbursement rate to the hospital market basket to provide for inflation. Unfortunately, these increases have not kept pace with the expense of delivering specialized care to dying Americans. A report 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." The factors that M&R cites as contributing to hospice losses are "new technology, including breakthrough therapies and prescription drugs."

For example, when Medicare set hospice payments in the 1980s, prescription drugs for hospice patients represented about \$1 of the per diem reimbursement rate. These costs increased to approximately \$16

per day by the late 1990s--an increase of about 1,500 percent. There is a drug, Epogen, being ordered by physicians for some of my patients that costs \$250 per dose. One patient received three doses per week, which ate up my entire Medicare reimbursement. Duragesic, a commonly used pain reliever 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.

Outpatient procedures for relief of pain, like chemotherapy and radiation therapy, have also increased. At my hospice, the increase in costs for these procedures has been 46 percent since 1996. My Medicare reimbursement has gone up 6% in that same time frame. Since between 85 and 90 percent of my patients each year are under Medicare, you can see what a problem I have in being able to make ends meet. The only way I have found to continue to provide services is through the charity of people in the communities we serve. Of our \$4 million budget, \$500,000 comes from gifts and memorials each year. Without these gifts, Hospice of North Iowa would have to close its doors.

In the last two years, my hospice has lost \$362,400. My annual budget is only \$4 million. At the same time, my staff are working harder than they ever have and have instituted aggressive measures to reduce costs. We are not spendthrifts. My staff work for hospice because they have a sense of mission. Any of them could get better paying jobs at any time--yet they stay with Hospice of North Iowa because they believe in what we are doing. Despite their lower pay rates, it is still costly to recruit, train, and retain staff. These costs are no less because we are located in a rural area, yet our reimbursement is reduced because of that fact. The routine home care rate paid for hospice care in an urban area is \$98.96. The fiscal year 2000 Medicare routine home care rate for my hospice is \$87.33. It costs twice that to spend a night in a Washington DC hotel room. Yet it is supposed to cover all costs related to a terminal illness, including physician oversight, nursing, counseling, spiritual support, bereavement counseling, medical equipment, drugs, home health aides, homemaker services, physical and occupational therapies, dietitians, and volunteers. Bereavement counseling and coordination of volunteers are Medicare mandated services that have been explicitly excluded from allowable costs in the new Hospice Medicare Cost Report.

Reimbursement has not kept pace with the increased costs of providing care. New drugs and other treatment modalities can greatly improve the quality of life for patients who are dying. We in hospice know how to alleviate pain and control symptoms. But, far too often, the skyrocketing cost of such treatments forces us to seek other, less expensive and perhaps less effective alternatives. A Lewin study done in 1995 indicated that \$1.52 could be saved by the Medicare program for every \$1.00 spent on hospice care. There is room to increase hospice rates to more accurately reflect costs of care while still saving money for the Medicare system overall. As the Medicare Payment Advisory Commission has stated, "the 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."

It is important that fraud and abuse of the Medicare system be eliminated. However, aggressive efforts to discover and prosecute fraud and abuse has resulted in a great deal of attention to a very small percentage of hospice patients who outlive their six-month prognosis. This has created an environment of fear among referring physicians and hospices that has limited access to hospice care. I recently had a patient in my hospice program who was discharged because she had been with us some months and had reached a plateau for a short period of time. Staff were concerned that Medicare would refuse payment for her care--as, in fact, it did. This patient died just six weeks after her discharge from hospice. During that six weeks, she needed our services as her health dramatically declined. But this had happened before when she had been our patient and she had not died. So everyone was fearful of readmitting her because of the regulatory oversight that questions care in cases such as hers. She spent her final two days with us--when it was very apparent that she was actively dying.

The Medicare Hospice Benefit is a wonderful service for Medicare beneficiaries. But reimbursement for this benefit must keep pace with the cost of providing care. In addition, admission criteria should be reviewed to encourage earlier admission to hospice care so that opportunities for physical, psychological, and spiritual support may not be missed for individuals at the end of life. I strongly support an update of hospice reimbursement based on current costs of care. I also endorse a Medicare waiver for demonstration projects that test alternative eligibility criteria for the Medicare Hospice Benefit.