

**THE END OF LIFE: IMPROVING CARE, EASING  
PAIN AND HELPING FAMILIES**

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**HEARING**  
BEFORE THE  
**SPECIAL COMMITTEE ON AGING**  
**UNITED STATES SENATE**  
ONE HUNDRED SIXTH CONGRESS  
SECOND SESSION

WASHINGTON, DC

JULY 17, 2000

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# **THE END OF LIFE: IMPROVING CARE, EASING PAIN AND HELPING FAMILIES**

**MONDAY, JULY 17, 2000**

**U.S. SENATE,  
SPECIAL COMMITTEE ON AGING,  
*Washington, DC.***

The committee met, pursuant to notice, at 1:30 p.m., in room SD-628, Dirksen Senate Office Building, Hon. Charles E. Grassley, (Chairman of the Committee) presiding.

Present: Senators Grassley, Craig, Burns, Collins, Hutchinson, Breaux, Wyden, Reed, and Lincoln.

## **OPENING STATEMENT OF SENATOR CHARLES GRASSLEY, CHAIRMAN**

The CHAIRMAN. I am Senator Chuck Grassley. Senator Breaux and I are the leaders of this committee. I am Chairman and he is Ranking Minority Member. I would like to welcome you all to today's hearing about "The End of Life: Improving Care, Easing Pain and Helping Families." Thanks to all of you for your interest in this very important issue.

Here on the Aging Committee, we have spent a lot of time over the last 4 years discussing the aging of American society. It is a very dramatic change in the life of our nation, and as time goes on and baby boomers retire, obviously, it is going to be a much more important problem as we go through the biggest demographic shift in the history of our country. So, this dramatic change of life stems, in part, from the huge increase in births in the postwar area, but it also is very dramatic in another way, and that is that we are living longer than the generations that came before us. Of course, this is much more a blessing than a curse.

Our forebears could hardly have imagined the longer and fuller lives that we are now able to live. But even with the tremendous advances that science is bringing, there is one thing that has not changed, and that is that dying is and will remain a part of our life. With the aging of the general population, more and more Americans will find themselves witnesses to the dying process, as caregivers for loved ones. Studies show, however, that the general public lacks the knowledge to be good consumers in this area.

Most of us know little about the availability of good care for the dying, including elements such as hospice and pain care. In addition, health-care providers are uncomfortable talking to their patients and their loved ones about dying. They also tend to be uninformed about what constitutes appropriate pain relief.

One of our witnesses today, now at the table, Ms. Shelly Twiford, will be relating her painful experience with inadequate end-of-life care for one of her loved ones. It is the story of inadequate pain management and frustration interacting with health-care practitioners. It is the story of being kept in the dark until her mother was virtually at the point of death, robbing the family of the ability to deal with the event on their own. Sadly, I do not think that her situation is unique today. In fact, it is all too common.

We will also be hearing from Ms. Peggy Gulotta, who will relate a much more satisfying story, one in which her loved one was treated humanely and with care. The question we will be asking today is this: how can we as a nation move from having experiences like Mrs. Twiford's toward experiences like Ms. Gulotta's?

Many have concluded that the end-of-life care education for both the public and the professional care providers is the best tool to bring about a transformation. Some encouraging efforts in this area have begun, and from our second panel, we will learn more about those efforts.

I would like to mention that this committee will hold another hearing in September, focusing on the Medicare hospice benefit in particular. Senator Breaux, Senator Wyden and I have asked the General Accounting Office to report to us on the barriers to more widespread use of hospice care and we plan to examine that in that hearing, and that would be sometime during mid- to late-September.

Some may consider this subject we are discussing today, and again in September, to be a depressing one for a hearing, but you will learn from our witnesses that it really is not. Death is a fact of life. Taking some measure of control over the last part of our lives and making it a fitting conclusion is a profoundly hopeful and uplifting idea.

So, I would now ask Senator Breaux to make his comments and maybe to speak about his constituent who is with us.

#### **STATEMENT OF SENATOR JOHN BREAUX**

Senator BREAUX. Thanks once again, Mr. Chairman, for convening this hearing of the Aging Committee in order to explore issues that are incredibly important, not just to the aging population of Americans, but also to their children and to their grandchildren, as well. This is one of these hearings that the Aging Committee, I think, has the ability to really do a great deal of good, not necessarily in passing a bill or talking about an amendment or handling legislation, but really trying to educate and make the general public aware of what is becoming a—I think, more and more an important topic for discussion. That is how people spend their final years and months and, indeed, days and hours in this life, and how they are treated, what services are available to them and perhaps what services are lacking.

They say that the only thing certain is death and taxes. Well, we can legislate about taxes, which we are doing right now, but there is not a great deal that we can legislate with regard to death. There are some things that I think the American public, as well as this committee, in particular, I think, can consider.

It is obvious from the facts that the life expectancy, the median age, at the turn-of-the-century was 47 years of age. Now it is about 77. So, people are living much longer than they used to. But it is not just a question of living longer. It is also a question of making certain that we try to allow people to live better and, in particular, it is important that in the last period of their lives, that everything is being done to make sure that it is spent in an atmosphere that is conducive of what we would like to say is a right that all Americans have.

It is interesting that only a very small number of medical schools in this country really have any courses or deal up front with the whole question of caring for the dying, because they are trained to keep people alive, but yet they are still very much involved in the final period of a person's life. I think that, hopefully, our committee can bring some of this information to the attention of the general public. In the education phase of our Aging Committee, I think this is an important role for us.

I, personally, have had the experience of helping my family deal with my father-in-law, who spent his last period of life in a hospice program. I thought how fortunate we were to have had that experience, to have had that service there, and how important it is that everybody knows of the type of things that are, in fact, available. Hopefully, our hearing today will shed some light in that area.

I am delighted to have Mrs. Gulotta appear, who came up from New Orleans this morning. I am delighted to hear from you, as well as the other witnesses on the panel. So, thank you very much for getting us off to a good start.

The CHAIRMAN. Thank you, Senator Breaux. I have referenced each of you. I did not say that Ms. Twiford is from Dakota City, NE and Ms. Gulotta is from New Orleans, I believe. From that standpoint then, tell us anything else you would like us to know about you, otherwise we are ready for your testimony.

Would you start out, Ms. Twiford.

#### **STATEMENT OF SHELLY TWIFORD, DAKOTA CITY, NE**

Ms. TWIFORD. Good afternoon. My name is Shelly Twiford. My mother died about 1½ years ago and I want to tell you about our experience.

In April 1998, my mother had surgery to remove a tumor in her head. We were told the brain tumor was secondary, coming from someplace else. As I look back, I believe the surgeon tried to prepare us by saying we all have a certain number of hours, days and minutes in which to live our lives.

My mother began chemotherapy treatments and the tumors responded wonderfully. Mom was extremely weak and we just chalked it up to the treatments, but Mom became weaker and weaker and, once a very active and energetic person, by September, was totally dependent on us, her family, for dressing, bathing, walking. She began losing her balance and falling.

My father was my mother's full-time caregiver and shouldered the burden without complaining. Although I do have to admit, tempers were flaring and times were getting harder. We all thought, if she just tried harder, maybe things would be OK. In September, my mother was hospitalized because she became so weak. My aunt

asked about hospice care because her sister-in-law had utilized the services. The physician's response to us was, "This is not about your sister-in-law and I'm not going to waste my time doing a job that a social worker can do."

In October we had to stop chemotherapy. My mother was too weak and too sick to continue. She began to have tremors as if she had Parkinson's Disease. Her legs were tingly and she could not feel anything. She had no quality of life. This was not who she was or who she wanted to be and we were in a financial mess.

My parents had no income other than Social Security. We called the courthouse to find out about financial assistance, but there was so much paperwork, we just could not wade through all of it. It was so overwhelming. They asked for so much information. My mother cried because she thought they were going to have to sell their possessions, the things that were so much a part of their lives. In order to help out, my brothers, my sisters and myself shared the financial burden of the medical and medicine costs.

The week before, on Thanksgiving, a CAT scan showed there were more tumors. I remember the doctor holding the film up to the light and pointing with his pen, "Here, here, here and here. They are too numerous to count." The doctor wanted to start radiation treatments the following day. I asked, "Could we have one day to wait and to think about it?" He said, "No, I think we need to start right away." The radiation consultation was that afternoon and the next day her treatments began. She was only able to receive about 10. Her face, hands and feet started to swell. She was in and out of the hospital during this time. We felt that if they were still doing the treatments, there must be a chance of curing her cancer.

She went home, but she continued to get sicker and weaker. It took two of us, usually my father and myself, to keep her from falling. She was unable to urinate, and not knowing what else to do, we finally called the ambulance and went to the emergency room. We were told then that we could not continue bringing her to the hospital. I felt like I had to plead with them to find a reason to keep her. They finally admitted her.

We were physically, emotionally and financially exhausted. There was not one thing left for us to give her. Realizing my mother was very sick and that we needed to stop this craziness and take her home, because that is where she wanted to be—but, the doctor wanted to move her to a rehab unit for physical therapy. At that time, we refused as a family. We stood our ground.

Planning for discharge, the hospice nurse came to visit my mother. She told us if we were going to take my mother home, we needed to move very quickly. During the night my mother had a heart attack. We were not notified of the change in her condition until we arrived the next morning, which was Tuesday. At 3 p.m. that afternoon she slipped into a coma. That evening a physical therapist came to my mother's room to start therapy. We ordered him to get out. At 1:05 a.m. on Wednesday morning, my mother died in the hospital surrounded by her family.

The questions that continue to haunt me, and No. 1, this is the biggest one, at what point in my mother's illness did she become terminal and who knew? We did not know time was so short. I did

not understand how a hospice nurse could tell, after just a very few short minutes, that my mother was dying and no one else knew. There was such a focus on her treatment, no one saw she was dying.

I tried to think of things that could have made my mother's death better for her and us, as her family, and here are a few of my suggestions. Be honest with the patient and their family. The important part of my mother's illness was missed and that was the simple fact that she was dying. We needed information about option and support services for physical, emotional and financial needs.

We looked to our health-care professionals to tell us when we should stop treatment. The last month-and-a-half of my mother's life were living hell for her and my father, and it did not have to be. We needed someone to recognize we were in trouble and needed additional assistance. We should not have had to forge this battle alone.

I realize that I have just a few short seconds left, but I have to tell you this story. As I look back on it, I remember after the first few chemotherapy treatments with my mother, they took us to this wonderful room, and it was a big-sized room, with hundreds of wigs. My mother had lost all of her hair. They had a wonderful lady called the wig-lady, who helped find a perfect wig to fit my mother's little bald head.

But, you know, as I think back on it, if they could have just had one room, one door we could have opened that would have given us the professionals that we needed; maybe her medical doctor, her oncologist, her radiologist, anyone who could have told us the one simple truth. Your mother is terminal. She is dying.

I thank you for listening to my story. I know that I cannot make a difference for my mother, but if I could help just one other person, then this has been worth the battle. Thank you.

[The prepared statement of Ms. Twiford follows:]



**Testimony of Shelly Twiford  
Before the  
Special Committee on Aging  
United States Senate  
July 17, 2000**

Good afternoon. My name is Shelly Twiford. My mother died about one and a half years ago and I want to tell you about our experience.

Before I tell you about how my mother died—I think you should know a couple of things about her life. I want you to know how she lived.

My mother and father were married for 52 years and lived in the same two-bedroom house for their entire marriage. They raised six children. Mom always loved children and opened our home to other kids, some of them staying for months. She had a huge rose garden and spent hours tending her flowers. She also loved to fish and crochet.

In April 1998, my mother developed a bump on her head ---we took her to the doctor. To be safe, he did a CAT scan. A week went by and we heard nothing. I was worried, so I called the doctor's office, and we were sent to see a surgeon that afternoon. The next day, my mother had surgery to remove the tumor in her head. We were told the brain tumor was a secondary cancer that had come from some other place in her body---later we found out the tumor was a lung tumor that had spread to her brain and her bone. The doctor told us she would need chemotherapy and radiation treatments. As I look back, I believe the surgeon tried to prepare us by saying that we are all given a certain number of days, hours, and minutes to live our lives.

The doctors told us that we had a choice of treatments. Either we could choose a normal course of treatment or opt for a new drug protocol. We chose the protocol therapy because we thought this might use new types of drugs and would offer more hope in treating the tumors. The tumors responded wonderfully to the chemotherapy. Mom was extremely weak, and we just chalked it up to the treatments. We were so relieved that we had made the right decision.

But Mom became weaker and weaker. The last time I remember her in the garden was in May. In two short months, Mom lost her ability to garden. Once very active and an energetic person, by September, she was totally dependent on the family for dressing, bathing, and walking. Dad found her a walker, but she was losing her balance and began falling.

My father was my mother's full time caregiver. I would help during my lunch hours and would stop off after work to lend a hand, but my father shouldered the burden without complaining. I have to admit it was getting harder. Tempers flared at times. We all thought if she would just try harder to get well, everything would be ok.

In September, my mother was in the hospital because she was so weak. My aunt asked about hospice care because her sister in law had been assisted by hospice. The physician's response was "this is not about your sister in law and I'm not going to waste my time doing a job a social worker can handle."

In October, we had to stop the chemotherapy. My mother was too weak and too sick. She began to have tremors—like she had Parkinson's disease. Her legs were tingly and she couldn't feel anything. She had no quality of life. This was not who she was, or who she wanted to be.

We were in a financial mess. My parents had no income, other than social security. We called the courthouse to find out about financial assistance. There was a ton of paperwork—we only got through part of the papers. It was so overwhelming, because they asked for so much information. My mother started crying because she thought they were going to have to sell their possessions—the things they had been so much a part of their lives. In order to help out, my brothers and sisters divided the medical and medicine expenses to relieve some of the financial burden.

The week before Thanksgiving, a CAT scan showed there were more tumors. I remember the doctor holding the film up to the light and pointing—"here, here, here, the tumors are too numerous to count". The doctor wanted to start radiation treatments the following day. I asked if we could wait one day to think it over, and he said no—I think we need to start right away. The radiation consultation was that afternoon. The next day, the therapy began and she only received about ten treatments. Her face and hands started to swell. She was in and out of the hospital during this time. We felt if they were still doing treatments, there was still a chance of curing the cancer.

She went home but continued to get sicker and weaker. It took two of us, usually my father and myself had to support her and keep her from falling. She was unable to urinate and not knowing what else to do—we called the ambulance and went to the emergency room. We were told we could not keep bringing her to the hospital. I felt like I had to plead to find a reason to keep her in the hospital, and they finally admitted her. We were physically, emotionally, and financially exhausted—there was nothing left to give.

Realizing my mother was very sick---we needed to stop this craziness and take her home because that was where she wanted to be. The doctor wanted to move her to a rehab unit for physical therapy, but we refused. Planning for discharge, the hospice nurse came to visit my mother. She told us if we were going to take my mother home, we would need to move fast. This was Monday, and we were planning for discharge on Wednesday. During the night, my mother had a heart attack. We were not notified of the change in her condition, and when we came into the room Tuesday morning we noticed she was having trouble breathing. Later that afternoon, she slipped into a coma. That evening, a physical therapist came into my mother's room to start therapy---we told him to get out. At 1:05 AM on Wednesday morning, my mother died in the hospital, surrounded by her family.

The question that continues to haunt me---is at what point in my mother's illness, did she become terminal---and who knew. We didn't know time was so short. I do not understand how a hospice nurse knew in a few minutes that my mother was dying and no one else knew. There was such a focus on treatment---no one saw she was dying.

I tried to think of the things that could have made my mother's death better for her and us, as her family. These are a few of my suggestions:

Be honest with the patient and their family. The important part of my mother's illness was missed and it was the fact that she was dying.

We needed information about options and support services for physical, emotional, and financial needs.

We look to health care professionals to tell us when we should stop treatment---the last month and a half were living hell and they probably didn't have to be.

We needed someone to recognize we were in trouble and needed additional assistance. You shouldn't have to forge this battle alone.

Thank you, for listening to my story. I know that I cannot make a difference for my mother, but if I can help one other person, that will assist me in coping with the loss of my mother.

The CHAIRMAN. Thank you very much, Ms. Twiford. Now, Ms. Gulotta.

#### STATEMENT OF PEGGY GULOTTA, NEW ORLEANS, LA

Ms. GULOTTA. My name is Peggy Gulotta. I am here today to tell you about the last 3 weeks of my husband's life. My husband was a physician, Carl J. Gulotta. He was a specialist in Internal Medicine. He served his country for 4½ years in the Pacific Theater and then when he returned, he practiced for 50 years before he retired. He adored his work and his patients adored him. I am very proud to say that in all of those 50 years, there was never a malpractice suit filed against my husband.

The years between 1995 and 1999 were very, very hard on him. First, he underwent quadruple bypass surgery. And when he recovered from that in the ICU, he never spoke again, a word maybe every 6 months, but he was never able to form a sentence or never able to give us his thought. Shortly after that, he was diagnosed with prostate cancer and he underwent 37 radiation treatments, which left him with chronic diarrhea for the rest of his life. But, the hardest diagnosis of all was Alzheimer's disease.

In the beginning, we were able to do very well at home. We had good services, good help and he was happy in the home that he had lived in for the last 40 years. However, in 1996, we were unfortunate to be in an automobile accident, which has left me permanently impaired, and I could no longer do for him the things I had previously done, nor was I able to scout around and get good health care.

I was fortunate, though, to find a small Alzheimer's-care home in the city. There are a group of them and they take as many patients as they have private rooms, and so he was lucky enough to get in one—have his own room. It was close to where we lived and I could visit him every day. I tell you all of this just as background information for the last few weeks of his life.

Now, one of the things that often causes the death of an Alzheimer's patient is they lose their ability to swallow, and that was the case with him. In the beginning, he would take something and he would choke on it. This gradually became worse. So the final hospitalization that he suffered was because he could not even dissolve and swallow the tiniest chip of ice without choking.

We both have living wills, so a feeding tube was absolutely out of the question. Our internist called a family conference, because I had had time to get my children and his grandchildren all there from the various cities they lived in. And at that family conference we were told that he only had a short time to live, but that he was no longer entitled to stay in the hospital room where he was. He had to be shifted to a unit in the hospital that is known some places as a Skilled Nursing Unit. Other places it is known as Respite Care.

At that family conference, the lady who was the supervisor of the Alzheimer's-care home that he lived in was present with us. She suggested an alternative or an option. That was to take him back to his room in the home where he had been living and get hospice care. So, our family decided that was the best for him. When we got him back there, he was happy. He was relaxed. He was in sur-

roundings that he was accustomed to, and we did not have him out of the ambulance 10 minutes before the hospice people were there.

I cannot tell you how wonderful they were. They were wonderful to him. They saw to his comfort. They saw to his medical needs. They saw to the emotional needs of each member of the family. They had a chaplain who saw to the spiritual needs. They were there every day, many times a day. The remarkable thing was when you called for help, it was not 6 hours coming. It was 10 or 15 minutes coming.

It put all of us at ease and we were able to accept his death, see him calmly pass away. He died in my arms. My children were all there, each one of them holding his hand, holding onto his foot. His brother, who is a retired judge, was standing by to sustain us. It was as peaceful a death as you can imagine under absolutely horrible previous circumstances.

I cannot speak highly enough for hospice care. He died in October and they have continued to keep up with my family since then. They called to see if we need any counseling, anything.

I appreciate being invited to participate in this, and I hope that what I have had to say may someday—I hope you never need it—but, I hope if you ever do need someone to help a loved one die, that you will consider hospice. Thank you.

[The prepared statement of Ms. Gulotta follows:]

**TESTIMONY OF PEGGY GULOTTA**

**Before the**

**SENATE SPECIAL COMMITTEE ON AGING**

**JULY 17, 2000**

**TESTIMONY OF PEGGY GULOTTA**

My name is Peggy Gulotta and I am here today to tell you the story of the last months and weeks of my husband's life. My husband, Dr. Carl Gulotta, was a physician with a specialty in internal medicine. I am proud to say that he practiced for fifty years and didn't have one lawsuit filed against him.

The years from 1995-1999 were very difficult years for my husband and myself. We both had medical complications--Carl's were more severe, as he required bypass surgery, was diagnosed with prostate cancer and lost his ability to speak, something we found out later was the result of Alzheimer's Disease. The effects of one treatment after another seemed to make things much worse. The really difficult one was the radiation treatments for the prostate cancer, which affected his bowels. That problem paired with his confusion made it very difficult to manage his care. We were able to get help and really managed quite well using a variety of resources that included day centers for Carl.

During this period, Carl and I got into a fairly bad car accident and the accident created a permanent disability for me. When I required multiple surgeries and a long rehabilitation period, I had to make the decision to place Carl in 24 hour care. In many ways this was a wise decision for both of us. He adjusted well to it and we actually were able to spend time together. We were fortunate to find a small group home that specialized in the care of Alzheimer's patients. It was a lovely homelike environment that provided supervision and care without feeling institutional.

But this is all background to the piece of the story I am really here today to tell you. What I most want to share with you is a description of the final few weeks of my husband's life. It is not something that one often talks about, because there is nothing worse than the loss of one's spouse. However, the last few weeks of my husband's life were very good in that we found services--services that we didn't know existed--that made all the difference in the world to my family.

As my husband's Alzheimer's progressed, he began to experience a symptom that I later learned was very common in advanced Alzheimer's patients--difficulty swallowing. Carl's final hospitalization resulted in a conference that stated that without tube feeding Carl would likely live a very short period of time. Hospital physicians suggested a skilled nursing unit where he could be kept comfortable. But, years earlier, in his living will, Carl had made the decision not to have a feeding tube so we all knew what Carl's wishes were on that.

Fortunately, the representative from the Alzheimer's group home where he lived introduced us to another option--hospice. All we wanted as a family was his comfort. I just wanted him to be able to go back to the place he called home and we learned that was possible with hospice care. It was hospice that allowed our family to share my husband's dying process with him just as we had shared his life with him.

There were several things that were most important from the time we knew that Carl was really dying. First of all, I was able to contact all of my children and allow them the chance to be

with Carl as he lived through his final days—they were all around him as he died. Carl's brother—a retired judge—was also there with us. Another was the fact that my husband had a choice about where he could die and he truthfully had a say in that decision—even in his confusion. Where he was restless and uncomfortable in the hospital he relaxed in his familiar environment. Also, we were all encouraged by the hospice folks to cry whenever we felt the need to—even my sons. I said I didn't want Carl to see me upset. They told me that Carl might be more upset if he didn't see how much I cared. We received support and encouragement. We were introduced to new ideas about how to interact as a family and especially with Carl. Most important of all is the fact that I can tell you that my husband died in my arms.

We were given an opportunity to tell him goodbye and to see him go in a manner that was comfortable and peaceful. The medical needs were met, he was comfortable and peaceful, and he was not in pain. We were able to be together as a family one last time. It was a process that I didn't know existed and I think most people don't know about it either. It becomes a very natural part of the life process. We need to learn a way to share the process so that everyone has access. People should know that there is a way to finish life with comfort, dignity, love, family and peace. It is equally important to know that the services should not end with the memorial service. I know in my instance, Carl died last November and people from the home where Carl lived are still in contact with me. This is what makes a difference in difficult times for those who leave through death and for those of us who remain in life.

Thank you for giving me the opportunity to testify today. I hope my comments can make a difference for others who face the same situation.



The CHAIRMAN. Thank both of you for diverse stories that you tell, but very important for us, as a committee, and the public at large, to hear the different points of view. We will have 5 minute turns at questioning.

Ms. Twiford, I want to thank you for sharing your experience with us. I can appreciate how hard it was for you to go through that again. By appearing here, of course, you're helping us and society at large to change things so that it will be better for others in the future.

It is appropriate to focus on the person who was dying, but I would like to ask you about your experience and how it might have been different. For instance, if the doctors had been more forthcoming about your mother's prognosis, what would you have done differently as a caregiver and what difference would that have made in your life during your mother's last few days, few weeks?

Ms. TWIFORD. Well, I think the biggest thing is my family would have had an opportunity to learn how to let go, instead of how it became a total emergency at the very end. We still were not sure what was going on. If they requested physical therapy, did that mean she still had a chance at life? We just were not sure. So the thing is, if we would have been given the prognosis in the beginning, we would have had a chance to let go, instead of the way we were left feeling as if we gave up and lost the battle.

So it was extremely difficult emotionally, financially, you know, we just were not prepared. She did not get to die at home in the home that her and my father had built, you know, 46 some odd years ago, but in a hospital, on a day when I had to call of my siblings from all over the country and say, "If you cannot get home now, it is going to be too late." I mean, I just cannot believe that someone in the beginning did not know that she was terminal and point us to the right door, to the right direction for that perfect fit that my parents needed.

The CHAIRMAN. Let's focus on the doctors that you dealt with. Did any of them seem interested in giving your mother or your family any control over what treatment was used, and did they pay attention to her reports of pain and discomfort?

Ms. TWIFORD. The pain I believed was managed. If we asked her on any given day, "Mother, do you have pain?" She would normally say no, until maybe the last week or so when she was unable to urinate or anything.

I do not believe they ever focused on who my mother was as a person or our family. I believe the focus was totally on curing the disease, but as I look back on it, hindsight 20/20, my mother's form of lung cancer, I know now, was terminal from the very first day.

The CHAIRMAN. One alarming aspect of your story is that you actually knew enough to ask about hospice care, but one of your doctors apparently dismissed hospice care out of hand. If you could speak to that doctor again, knowing what you know now, what would you tell him?

Ms. TWIFORD. I would tell him I need him to be honest. I needed him to set us on the path to allow my mother to die respectfully and at home with her family. I do not pretend to know the reasons why he chose not to make hospice available to our family. I have

no idea. All I know was that something truly was missed somewhere, and that was the fact that my mother was dying.

The CHAIRMAN. Ms. Gulotta, what advice would you give to anyone else who finds themselves in such a situation as you did, based on your experience, during what you considered more horrible aspects of it versus the more positive aspects of it?

Ms. GULOTTA. Well, the most positive aspect of his death was certainly when we got hospice care. I knew nothing about hospice care. Had it not been for the lady who was the supervisor of his Alzheimer's home, I would not have known anything about it.

So I have her to thank for that. My doctor, his doctor did not recommend it. He just recommended a shift to the other unit in the hospital, but hospice care, if it is good, is the best care a person can die with. You can only receive it if it is expected that your death will come within 6 months. In our case it was less than 2 weeks.

The CHAIRMAN. Senator Breaux.

Senator BREAUX. Well, thank you very much, Mr. Chairman, and let me, particularly, thank both of our witnesses for sharing something that obviously is always difficult to have to deal with. But, I think in doing so, you certainly allow us to communicate to the rest of this country about the things that you two went through with your loved ones.

I was wondering, Ms. Twiford, from the time that your mother was diagnosed with lung cancer to her passing away; how long of a period was that?

Ms. TWIFORD. Nine months.

Senator BREAUX. I take it that—you said in your testimony that really up until almost the last day before she passed away, they were still sending the physical therapist to the room to do physical therapy?

Ms. TWIFORD. Right, and radiation. They continued to try to radiate her brain right up until the last week, when we would physically have to lift her in and out of the vehicle to get her there, put her in a wheelchair and take her in. She repeatedly told us, you know, I cannot continue to do this; but until someone told us that it was time to stop, we really thought maybe she had a chance.

Senator BREAUX. Was there any time during that 9-month period that any of the treating physicians or hospital personnel came in and said, "Look, we would like to talk to the children about your mother's condition," and explain the fact that she was terminal and that you had some decisions to make?

Ms. TWIFORD. Absolutely not, no time during her 9-month illness. We did have her neurosurgeon, bless his heart, the first person I told you about, who said we are all given a certain amount of hours, minutes and days, explained my mother's condition like this: A large airplane flying over and a bunch of parachutes fall out, and where they land, that may be where the tumors grow. Now, those words from him were the first and last reference to anything terminal.

Senator BREAUX. That is hardly a good explanation of what your mother was facing.

Ms. TWIFORD. Hardly.

Senator BREAUX. I think one of the things that we were talking about, the committee, that there are only four, I think, of the Nation's 126 medical schools that even have courses on treating of dying, because doctors are taught to treat people to keep them alive and healthy, and I guess that—it seems to me that they are not preparing the medical profession for treating the person who, in fact, is dying, and also to work with the families in the way that they should.

Hospice, Ms. Gulotta, on the other hand—I think your experience with them was very positive, as mine was with my father-in-law. He was at home and had hospice there for regular visits, and it prepared not only him, but the rest of the family for what was happening. But it would seem that the medical profession should be involved in this at an earlier time than they were.

I take it that—it seems to me, and maybe some of the other experts can testify later on, that the decision to call in hospice itself, by the family, is a recognition of the fact that you think the patient is going to pass away within 6 months; and that in itself is an act that is a very difficult one to do, because you are sort of saying, "We are giving up on medical treatment and we know the inevitable is going to occur, so we are making a decision to call hospice."

I am wondering, what do you think the effect, if you could, on your mother or your husband would have been if at some point in that 9-month period and, Ms. Gulotta, some point after your husband's situation had developed, if you were to tell them that we are going to bring in hospice, what do you think—if you could maybe speak to that—what their reaction would have been?

I was always very concerned about that with my father-in-law, because if we call in hospice, we are telling him—

Ms. TWIFORD. That it is terminal.

Senator BREAUX [continuing]. That he is terminal, and I was concerned about that; and I was wondering, do you have any idea of how your mother and your husband would have accepted that?

Ms. GULOTTA. I believe, in the case of my husband, that he would have considered it a release from a prison that he would love to get out of, because he could not speak; he had chronic diarrhea. He could not have been happy. He was glad to see his family, but there was very little recognition even of his family toward the end; and had he had his wits about him, he would not have wanted to live like that.

Senator BREAUX. Ms. Twiford.

Ms. TWIFORD. Well, I feel the same way. I mean, maybe at the beginning it would have been difficult, the initial shock of knowing you are terminal. But, I mean, we all had to come to that conclusion, but we just had 24 hours to prepare.

I remember one of the last things my mother said to me that Tuesday was, "Well, kid, I don't want to go, but it looks like I'm going to have to." Shouldn't she have been able to prepare for that 5, 6, 9 months prior to the actual day that she left us? She did not have the time to let go. I mean, we had to crunch all that healing, all that anger, all that passion into about 12 hours.

Senator BREAUX. Well, both of you have been very helpful and we appreciate very much being with us and our committee today. Thank you so much.

The CHAIRMAN. Thank you, Senator Breaux.

Senator Craig.

Senator CRAIG. Mr. Chairman, first let me ask unanimous consent that my opening statement become a part of the record.

The CHAIRMAN. So be it.

[The prepared statement of Senator Craig follows:]

PREPARED STATEMENT OF SENATOR LARRY CRAIG

I would like to thank the Chairman for holding this hearing today regarding the important issue of end-of-life care. I would also like to thank each of the witnesses for taking the time to appear before the committee to testify.

While there has been a great deal of discussion and debate regarding health care reform and Medicare Reform, end-of-life care is not generally included in these debates. Yet many seniors and their families must deal with this issue every day. Numerous home health, hospice and nursing home providers in my State of Idaho also focus on the issue of end-of-life care in the course of their daily work. Together these groups can provide us valuable insight by sharing their experiences.

Sadly, too many seniors and their families cannot count on having the support and help they need coping with the physical, mental and emotional challenges of the twilight years. Science and technology have allowed many people to live longer and healthier lives; however, sickness and disability near the end of life are still inevitable for most of us. Increased professional education, public awareness and responsible pain relief are crucial to improve end-of-life care. We have here an opportunity to ensure that the people who depend on care from end-of-life care facilities are treated with respect and kindness. We need to investigate all solutions to this problem, including increased education for professionals and outreach programs to family members, and make sure we have a strong assistance system for these seniors.

My priority here is to look at constructive ideas and build a strong, safe environment for the many elderly who depend on end-of-life care. That's why I am glad Senator Grassley is holding this hearing and am hopeful that some good will come of it for the many families who deserve this help in what is probably a very difficult time for them.

Again, I would like to thank the Chairman and our panel of witnesses here today for addressing this important issue. I look forward to the benefit of the insight of today's witnesses. Thank you.

Senator CRAIG. Mr. Chairman, again let me also join in thanking you for holding these hearings, and I am sitting, listening to both of you, trying to figure out where was the difference; and obviously, at least, I draw some conclusions and I would like your reaction to these conclusions.

Most of us believe today that Alzheimer's disease, because we have not perfected a cure or a treatment, but more of a care to the individual who has it, is terminal. Different lengths of time, but generally terminal. As a result of that, I think I drew the conclusion that maybe the medical profession looks at the way you treat an Alzheimer's patient different than they do a cancer patient.

A decade ago, we would have said cancer, terminal. We do not say that today. We; in fact, are now very proud of the fact that the statistics have flipped on us. While the diagnosed cases of cancer are staying static or going up, the deaths are dropping; so we tend to react to cancer more so today as something that is possibly curable or that we can sustain life a great deal longer, and we think differently of it.

Also, my guess is that doctors treating cancer think in that mode. Doctors or caregivers thinking of Alzheimer's think differently. Your reaction to those?

Ms. TWIFORD. Well, first of all, I just want to say that maybe some cancer is curable, but what my mother had was small-cell

lung cancer that had spread to her brain. I mean, that is how we found the cancer, a bump on her head.

Senator CRAIG. Well, I did not get here for the first part of your testimony. I have not read it. That is an important factor.

Ms. TWIFORD. That is an important fact. So, I believe from the very day that the neurosurgeon removed the tumor and tried to tell us about the plane and numbers, days and hours, her diagnosis was terminal; but they forgot to tell some people, and those people were my mother and her family, so that we could have chosen a different path. I don't know. Maybe we still would have elected treatment for three or 4 months.

I mean, maybe in our minds, we still would have thought there was hope. But, by God, I know that the day before my mother died, I still would not be struggling to give her rehab or just keep her alive—for what reason, when the ultimate end is the same?

Senator CRAIG. Well, that is obviously a valid observation. There are certainly different kinds of cancer. I am sitting here saying what triggers the reaction of the caregiver to want to cause the individual and the family the best of circumstances in this end of life process that we are concerned about here? Obviously, your experience has been very negative. Obviously, yours ma'am, has been positive, and I am wondering if it is, at least in the general sense, the type of disease involved.

Ms. GULOTTA. I think doctors do not treat Alzheimer's now because there is not a treatment.

Senator CRAIG. That is correct.

Ms. GULOTTA. In the beginning, when you are first diagnosed, there are some medications that they prescribe. If they help, fine; if they do not help, they quit, and then that is about all they can do.

Senator CRAIG. Yes. Well, I thank both of you very much for your testimony. It is very enlightening as to concerns that I think—and problems that many Americans—well, probably all of us face at one time or another with our loved ones and ones that are close to us and we want to provide the best circumstances possible during that time. Thank you both.

The CHAIRMAN. Senator Craig, thank you.

Senator Collins.

Senator COLLINS. Thank you, Mr. Chairman. I want to thank you for holding this very important hearing on issues that all of us will confront sooner or later with our own families. I think Americans are generally very reluctant to talk about end-of-life care, and by holding this public hearing and by our two witnesses' eloquent willingness to come forward, I hope we are encouraging other families to talk about it before they have to confront the very painful situations that both of our witnesses had to deal with.

I do have an opening statement that I would like to include in the hearing record, Mr. Chairman.

The CHAIRMAN. Without objection.  
 [The prepared statement of Senator Collins follows:]

PREPARED STATEMENT OF SUSAN COLLINS

Mr. Chairman, thank you for calling this hearing this afternoon to examine ways we can improve the way that we care for people at the end of their lives. These are critical issues that at some point will confront each and every one of us, and I am pleased that the Aging Committee is focusing attention on them today.

Noted health economist Uwe Reinhardt once observed that "Americans are the only people on earth who believe that death is negotiable." Advancements in medicine, public health, and technology have enabled more and more of us to live longer and healthier lives. However, when medical treatment can no longer promise a continuation of life, patients and their families should not have to fear that the process of dying will be marked by preventable pain, avoidable distress, or care that is inconsistent with their values or wishes.

The fact is, dying is a universal experience, and it is time to re-examine how we approach death and dying and how we care for people at the end of their lives. Clearly, there is more that we can do to relieve suffering, respect personal choice and dignity, and provide opportunities for people to find meaning and comfort at life's conclusion.

Unfortunately, most patients and their physicians do not currently discuss death or routinely make advance plans for end-of-life care. As a consequence, about one-fourth of Medicare funds are now spent on care at the end of life that is geared toward expensive, high technology interventions and "rescue" care. While most Americans say they would prefer to die at home, studies show that almost 80 percent die in institutions where they may be in pain, and where they may also be subjected to high-tech treatments that merely prolong suffering.

Last year, I joined Senator Rockefeller in introducing the Advance Planning and Compassionate Care Act, which is intended to improve the way we care for Medicare patients at the end of their lives.

Among other provisions, the bill makes a number of changes to the Patient Self-Determination Act of 1990 to facilitate appropriate discussions and individual autonomy in making difficult decisions about end-of-life care. For instance, the legislation requires that every Medicare beneficiary receiving care in a hospital or nursing facility be given the opportunity to discuss end-of-life care and the preparation of an advance directive with an appropriately trained professional within the institution. The legislation also requires that, if a patient has an advance directive, it must be displayed in a prominent place in the medical record so that all the doctors and nurses can clearly see it.

The legislation will also expand access to effective and appropriate pain medications for Medicare beneficiaries at the end of their lives. Severe pain, including breakthrough pain that defies usual methods of pain control, is one of the most debilitating aspects of terminal illness. However, the only pain medication currently covered by Medicare in an outpatient setting is that which is administered by a portable pump.

It is widely recognized among physicians treating patients with cancer and other life-threatening diseases that self-administered pain medications, including oral drugs and transdermal patches, offer alternatives that are equally effective in controlling pain, more comfortable for the patient, and much less costly than the pump. Therefore, the Advance Planning and Compassionate Care Act would expand Medicare to cover self-administered pain medications prescribed for the relief of chronic pain in life-threatening diseases or conditions.

The legislation also establishes a telephone hotline to provide consumer information and advice concerning advance directives, end-of-life issues and medical decision making and directs the Agency for Healthcare Research and Quality to develop a research agenda for the development of quality measures for end-of-life care. In this regard, Senator Rockefeller and I are particularly appreciative that our recommendation that end-of-life care be added as a priority in the Agency for Healthcare Research and Quality's overall mission and duties was included in the legislation reauthorizing the Agency that was approved by the Congress last year.

Finally, the Advance Planning and Compassionate Care Act authorizes the Department of Health and Human Services to study end-of-life issues for Medicare and Medicaid patients and also to develop demonstration projects to develop models for end-of-life care for Medicare beneficiaries who do not qualify for the hospice benefit, but who still have chronic debilitating and ultimately fatal illnesses. Currently, in order for a Medicare beneficiary to qualify for the hospice benefit, a physician must document that the person has a life expectancy of six months or less. With some

conditions—like congestive heart failure—it is difficult to project life expectancy with any certainty. However, these patients still need hospice-like services, including advance planning, support services, symptom management, and other services that are not currently available.

In this regard, I introduced an amendment to the Patients' Bill of Rights, which was approved by the Senate, to require a comprehensive study into the appropriate thresholds, costs and quality implications of moving away from the current narrow definition in Medicare of who is terminally ill and toward a definition that better identifies those with "serious and complex" illnesses. This study was suggested by the group Americans for Better Care of the Dying, and is intended to help us shift the paradigm in this country of how we view serious illness. This study will help us to provide better care for that broader category of patients who are terminally ill and have a need for more coordinated care, but who will probably live for another year or two.

Discussions about effective pain management and appropriate end-of-life care are particularly appropriate in light of the current debate on physician-assisted suicide. The desire for assisted suicide is generally driven by concerns about the quality of care for the terminally ill; by the fear of prolonged pain, loss of dignity and emotional strain on family members. Such worries would recede and support for assisted suicide would evaporate if better palliative care and more effective pain management were widely available.

Mr. Chairman, patients and their families should be able to trust that the care they receive at the end of their lives is not only of high quality, but also that it respects their desires for peace, autonomy and dignity. This morning's hearing should be extremely helpful in our effort to improve care of the dying in this country, and I look forward to hearing from the upcoming witnesses.

Senator COLLINS. Mr. Chairman, most Americans say they would prefer to die at home, and yet studies show that almost 80 percent of them die in institutions where they may be subjected to high-tech treatments that merely prolong their suffering. Ms. Twiford, I thought of that statistic when I heard your story. Do you think that the reason the physicians were not more forthright with you about your mother's condition is that they were uncomfortable about talking to you about the fact that she was going to die?

Ms. TWIFORD. Well, I am not sure if it was the fact that they were uncomfortable. I really do not know what made them take the path they took. Maybe they just have—I do not know. It could be a goal financially. I mean, the longer they treat them—you know, I hate to think that in my own mind, but that could be part of it, or maybe they are just unwilling to finally give up on the medical part of the disease and say, you know, "We have done all we can." If I had the answer to that, I probably, you know, would have come to terms with the whole thing a lot sooner. I am still searching.

Senator COLLINS. I think it is so unfortunate, because we have heard from Mrs. Gulotta's case and others of very positive experiences with hospice. As you point out, your mother's condition, from the time it was diagnosed, it was probably obvious that she was going to die. It seems like her last few months could have been so much more peaceful for her and allowed her family to come to terms with her illness, as well.

Mrs. Gulotta, you raise a really interesting point about hospice care, and I share your very high opinion about hospice care. You mentioned that, in order to qualify for hospice care, a physician has to certify that the patient only has six more months to live. Maine has a wonderful system of very compassionate, skilled hospice providers throughout the State, but we have a very low rate of referral for hospice care compared to other States.

In talking with physicians, I have been told that that 6-month requirement is one reason why. Senator Rockefeller and I have in-

roduced legislation intended to improve Medicare reimbursements for caring for people at the end of their lives, to make sure that, for example, that pain medication that is administered within the home is reimbursable, and to give us more flexibility with that 6-month window in which the certification has to be made.

It sounds to me like your husband might well have benefited from hospice care earlier in the final stages of his life; but did you only become aware of it toward the last month when the Alzheimer caregiver mentioned it to you?

Ms. GULOTTA. Yes, only when the doctor called a family conference and said he had to be removed from his room in the hospital to another area, a different level of care in the hospital, that is when I became aware of it, and he was moved that day.

Senator COLLINS. Yet had he had hospice care earlier, it might have given you even more peace of mind and, as you said, helped him escape from the prison that he felt he was in. Do you think that is a fair statement?

Ms. GULOTTA. I think that is a fair statement, yes.

Senator COLLINS. It seems to me, Mr. Chairman, that something our committee should strive to do is to look at Medicare reimbursement policies and see if more flexibility is needed to make sure that we are not discouraging physicians from making referrals to hospices for patients that could well benefit from them; and that is the purpose of the legislation that Senator Rockefeller and I have introduced.

The CHAIRMAN. You may want to remind us, because in mid-September to late-September, we are going to have a hearing on end-of-life care in Medicare, and your provisions would fit very well into that discussion.

Senator COLLINS. Thank you. I am very pleased to know that, because that is something that I have been advocating for some time.

Ms. Twiford, did anyone, when your mother was admitted to the hospital, talk to her about any advance directives or living wills or any other directions that she wanted to provide to her caregivers, to help draw that line from when she did not want to seek more aggressive treatment?

Ms. TWIFORD. Well, actually, yes, we did cover that on the Tuesday that she slipped into a coma. My father and I had the papers drawn up, had a lady come who could notarize it. We ran to an attorney's office, got my mother's signature on everything that we needed to do, and we had to do that all within the last 8 hours of my mother's life. So, yes, things were signed, but we—

Senator COLLINS. But way too late. I mean, those questions were not raised when she first went in for surgery for the first tumors; is that correct?

Ms. TWIFORD. No.

Senator COLLINS. See, it seems to me that she was really failed by the hospital and her caregivers. I do not mean to judge, because I do not know exactly what went on; but it seems to me that when she was admitted with the diagnosis that she had, that is the very first time her physicians and the hospital people admitting her should have talked with her, to try to determine her wishes and—in case the diagnosis proved to be correct—and told her what her options were, and that never happened; did it?



Ms. TWIFORD. Well, we were given a choice. We were given a choice between what I remember them saying as a normal chemotherapy treatment and something called protocol; and we thought protocol was a new drug, was something that came out that would maybe give her a better chance, and so we chose protocol. But we were never offered a choice of managing the illness—her being terminal—and chemotherapy or treatment.

Senator COLLINS. Well, I think the answer you just gave shows that they did a terrible job of explaining to you what the options are, since you misunderstood what the protocols meant. That is so unfortunate. But, again, I want to join the Chairman and thank you for coming forward, because by telling your story, you will help other families avoid what you went through.

Thank you both.

The CHAIRMAN. Senator Collins, keep in touch with us on the next hearing that we have, because your legislation would be part of that.

Senator Burns.

Senator BURNS. Thank you, Mr. Chairman, and I have a statement for the record, to be included without your objection.

The CHAIRMAN. It will be included.

[The prepared statement of Senator Burns follows:]

#### PREPARED STATEMENT OF SENATOR CONRAD BURNS

Mr. Chairman, thank you. I would also like to thank those who are presenting testimony today. We all appreciate you for taking time out of what I am sure are busy schedules.

Montanans are proud and independent people. We grow strong as we battle environments which are not always kind to us. Most Montanans value their independence above all else, including their lives. So what happens when a Montanan begins to lose independence as they near the end of their lives?

Montana has one of the quickest rising Senior Citizens populations. By 2023, Montana will have the third highest proportion of Senior Citizens in the country, following only Florida and West Virginia. Unfortunately, Montana is not ready for this population explosion. Our health infrastructure is not ready to handle the increased demand for services that a rapidly aging population brings.

What we first must do is make sure that rural health care survives the next couple of years. While we have started to reduce the severity of the impact for the Balanced Budget Act, there is much work left for us. The delivery of medical services in truly rural environments such as Montana is tenuous at best. I call on my colleagues to join me in continuing the fight to protect rural health care. We can do this by adjusting Medicare reimbursement for all stages of the healing and the dying process.

It must be our goal to keep those who are near or at the end of their lives as comfortable as possible. I commend those involved in hospice care and thank them for their dedication to an area of our lives that we all devote significant thought to but rarely discuss with even the closest of friends and family. By promoting and encouraging the growth of our hospice industry, I believe that we can improve the ends of lives of those we love. Although death will always be a sad event for those who are left behind, with hospice care, I believe that we can help eliminate much of the tragedy surrounding the passing of a loved one.

I thank the Chairman.

Senator BURNS. I have no questions. I was sitting here and just giving some thought about my own parents. I was always sorry that I was not there when my dad died, but I was when my mother died. She died in 1997. Dad died in 1992. On a Monday, when I left Dad, and they were at home, I said I will see you next weekend—this weekend. I live in Montana. They live in Missouri. So, I can kind of fly into Kansas City and spend a few hours before

I go on down the way. I remember my dad looking up and saying, "I won't be here."

He had cancer, but he was also 86 years-old, almost 87 years-old. I think that kind of honesty in families is very important. I am sorry you went through the experience you had with the doctors in Iowa City. I can relate to that somewhat; and I do not know if there is any policy or law or anything, that we could write that could alleviate that, or even prevent it in the future, other than what the Chairman has done today with this hearing, this public hearing, to raise the public's awareness of those damages that we have in front of us whenever we start dealing with our parents and even ourselves as we move into that. I am over 65 now, you know. I am one of those just circling the drain here; but I think it is the honesty that we have to generate in our families that make us realize that this is a part of life. But, my dad, of course, he farmed in northwest Missouri, not too far from where you are from. People of the prairies, as you know, look at life differently than any other part of the world. I mean, they just do. They just accept it, especially farm people. They just look at those things and they understand it.

So, I just want to thank both of you for coming forward today. It is hard to tell those stories, because they are so personal and they are so close to you; but I just want to thank the Chairman for this hearing. It would raise the awareness. I do not know what we can do, other than be familiar with the feelings and those thoughts that rush through our minds whenever we lose a good partner and a wonderful mother. I can imagine what you went through. So, thanks for coming today.

Ms. TWIFORD. Thank you.

The CHAIRMAN. I have no further questions. Any of my colleagues? [No response.]

We thank you very much and you are welcome to stay and hear the next panel, if you want to. I appreciate very much your taking time out of your busy schedule to be here and sharing with us.

I am going to ask the next list of people to come as I introduce you. First, Joanne Lynn, M.D., President of Americans for Better Care of the Dying, Director of the RAND Center to Improve Care of the Dying, Arlington, VA; James Tulsy, M.D., Associate Director, Duke Institute on Care at End-of-Life, Associate Professor of Medicine, Duke University, Director of Program on Medical Encounter and Palliative Care, Durham Veterans Administration Medical Center, Durham, NC; Linda Todd is a registered nurse and Director of the Hospice of Siouxland, Regional Representative, Board of Directors, National Hospice and Palliative Care Organization, Sioux City, IA—Ms. Todd will describe the organization's new public engagement efforts, as well as her own hospice experience and increasing public awareness of care at the end of life; Dr. Richard Rosenquist, Member, Veterans Administration National Pain Management Safety Committee, Director, Pain Medicine Division, Associate Professor, University of Iowa, Iowa City; Dr. Rosenquist will discuss the Veterans Administration wide-ranging educational effort to improve palliative care; and Dr. Linda Emanuel, also Ph.D., Principal, Education for Physicians on End-of-Life Care Project, Professor of Medicine, Northwestern University.

We will go in the direction that I introduced you. So, Dr. Lynn, you will be first.

Senator BURNS. Mr. Chairman, can I just break in here? I want to apologize to Ms. Twiford. She is from Dakota City, not Iowa City. I know where both of them are.

Senator BREAUX. She knew where she was from. It was you. [Laughter.]

Senator BURNS. I have a fantastic memory, but it is just short. [Laughter.]

The CHAIRMAN. Now, Dr. Lynn.

**STATEMENT OF JOANNE LYNN, M.D., PRESIDENT, AMERICANS FOR BETTER CARE OF THE DYING; DIRECTOR, RAND CENTER TO IMPROVE CARE OF THE DYING, ARLINGTON, VA**

Dr. LYNN. Thank you. I am here on behalf of two organizations, Americans for Better Care of the Dying and the RAND Center to Improve Care of the Dying. For two decades, I have served the very sick here in Washington, D.C., long enough to appreciate just how significant it is for you to be having this hearing.

America's experience with illness and death has changed dramatically during the 20th century. While almost doubling the lifespan, we have also changed the cause of death from infections and accidents to cancer, strokes, heart disease and dementia. The care system reflects our inexperience with our new situation. While we know how to deliver surgery and emergency care, we simply do not know how to meet the needs of people who live for years with an eventually fatal chronic illness.

Our most need is to implement things we already know. The dying person who wants to stay at home needs no new device. She just needs the community to figure out how to get supportive services to her at home. Some of our problems as a community arise from using words and categories from an outdated perspective. If you have a look at the diagram there, people once assumed that a patient would generally get aggressive treatment until that was ineffective, and then the patient would turn the corner and have hospice care or supportive care, which included only symptomatic treatment.

This pattern did fit many patients with certain cancers, and that is the line that goes along with very good function and then a short period of dramatic decline toward the end. That is the way we built the hospice program, was the assumption that people would have a relatively short period of time which could be labeled as dying. Most of us, though, will be disabled by many months or years by diseases such as heart disease, emphysema, stroke and dementia.

We will have some serious complications, any one of which could cause death, and one of them will, but we will not know which one. Most of us now die in a week that started like many other weeks. We were very sick, but we were not sicker than we had been before. So this idea that there is a piece of time that is easy to label as dying actually misleads us.

More than half of cancer patients who are covered by Medicare now die in hospice care, which provides unusually coordinated and comprehensive care. Often, though, patients sick enough to die will never qualify for hospice care, since their prognosis is too uncertain

or the scope of service too narrow, they may not have skilled needs and be homebound, both of which are required for home care services under Medicare, yet they are terribly sick and fragile.

A major challenge for the first decade of this century is to learn to serve this large and growing population. Care at the end of life is improving. I will focus here on two endeavors; helping the public learn how to manage end-of-life issues and helping professional care providers learn how to improve practices. The public is eager to learn. Our Handbook for Mortals, which I have brought for you here, offers straightforward, common sense advice, helps people to take charge of the end of life, and includes poetry and metaphors, as well, since this is not really just about medical issues.

The poster shows one example from the handbook, advising patients on how to talk with the doctor and get the information you really need. Patients and families are desperate for this kind of information and insight. Television, for example, someone has called it our Nation's campfire, shows almost no stories of people living with serious and progressive illnesses. They are just not there. Our culture has kept serious long-term illness just hidden away. Thus, most people are bewildered and frustrated when they first encounter serious chronic illness, usually as their parents die.

Providers are also eager for improvements. Working with the Institute for Health-care Improvement and teams from nearly 100 provider organizations, we learned that improvements in serving the very sick can be made, and quickly. Nearly every team that stayed with the job for a few months made major improvements in something that matters to patients. For example, one hospital cut the time a patient had to wait for her pain medications in half, in 3 months. One hospice nearly eradicated serious shortness of breath. Nearly all the programs that worked with heart-and lung-failure patients cut their rate of hospitalization by 20 to 50 percent. One's trained nurses could come to the patient's home within half-an-hour to help with an exacerbation of symptoms. This cut the rate of using emergency rooms to well under half of the previous rate. How did our teams get these astonishing results? By using rapid quality improvement methods, which should now be part of the training of health-care professionals.

HRSA and AHRQ may well have a role in implementing the strategies more broadly. Medicare has a role, too, and that has already been mentioned. Seventy-five percent of us now die past 65. Medicare provides reasonably well for procedures and hospitalizations, but does not pay for continuity, self-care education, medications or caregiver support.

This pattern is almost perfectly mismatched with the needs of those who face dying. We urgently need a few years of substantial innovation and evaluation, learning how to build a care system tailored to our new demographics. This fall promises a substantial increase in public attention to end-of-life issues. Bill and Judith Moyers will show a four-part series on PBS in early September. Many magazines and newspapers are planning stories that are linked to this, including a multi-page insert from *Modern Maturity*. The Nation's public libraries and hospices will be sponsoring community meetings.

Demands for improvement will rise, and that improvement is within our grasp. Congress could take the leadership by creating a climate of innovation and reform. We can learn how to serve those coming to the end of life. That is all of us. But we have to start now.

Thank you.

[The prepared statement of Dr. Lynn follows.]

Testimony before the Senate Special Committee on Aging

July 17, 2000

Joanne Lynn, MD

President, Americans for Better Care of the Dying

and

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Mr. Chairman and distinguished members of the Committee, thank you for the opportunity to testify before the U.S. Senate Special Committee on Aging today. For two decades, I have served the sick and dying in Washington, DC, as a hospice, home care, and nursing home physician. I have been at it long enough to appreciate how significant it is for you to be having this hearing. Until recently, the fact that aging people inevitably die was simply swept off the agenda in public policy. The fact that we almost always become very sick before we die was seen as some sort of temporary inconvenience—we acted as if prevention and rehabilitation were all that health care policy needed to pursue. Reality is leading us to take seriously the simple fact that most of us will be elderly when we die, and that most of us will die of degenerative, disabling conditions. I am here on behalf of two organizations. Americans for Better Care of the Dying is a membership organization dedicated to public and professional education and aiming to make the end of life comfortable and meaningful for all Americans. The RAND Center to Improve Care of the Dying is a scholarly team that does research and supports quality improvement in order to provide the information necessary to shape policy and practice worthy to serve those with eventually fatal chronic illness.

Americans are likely to live for months or years with the diseases that eventually kill us -- and most of us will suffer from the inadequacies of a health care system that simply was never designed for people like us. Nor could it have been: from the perspective of most of the last century, a long and mostly healthy life would have seemed accomplishment enough. Changes in Americans' experience of illness and death during the twentieth century were truly astonishing. (See Table below from *Improving Care for the End of Life: A Sourcebook for Health Care Managers and Clinicians*, forthcoming from Oxford Univ. Press). The debates that shaped Medicare in the 1960's featured many patients who could not save up money for a surgery—but

very few who were suffering from long-term, implacably progressive, eventually fatal chronic illness. The care system reflects this—it was well-designed to ensure that surgery was readily available, but it simply did not anticipate the needs of people who would require medications and home health aides as they faced an eventually fatal chronic illness.

A Century of Change		
	1900	2000
Age at Death	46 years	78 years
Leading Causes of Death	infection accident childbirth	cancer heart disease stroke/dementia
Usual Place of Death	home	hospital
Most Medical Expenses	paid by family	paid by Medicare
Disability Before Death	not usually	>4 years, on average

We are learning to do better. When I first started working in hospice in 1978, most cancer patients came to hospice with terrible pain and had never been given any opioid medication (narcotics). Today, that would be scandalous. Some cancer patients still don't get adequate pain treatment, but virtually all have elementary use of opioids. In 1976, our society framed the request of Karen Quinlan's parents to stop her ventilator as a question of whether she might be said to have the "right to refuse treatment." Now, no one doubts that every patient has that right. Indeed, California and probably the United States Supreme Court have given patients the right to relief of pain. We are asking different questions, such as: "How do we arrange services so that people can count on good care? How can we train providers so that excellent care at the end of life is readily and reliably available? How do we empower patients and



families to ask for the kind of care they need, and to expect no less?" I will sketch the answers to these questions later in my testimony.

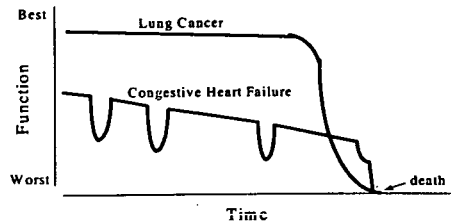
We have much to learn; we are new at this endeavor. Some insights will come from basic science research--better medications, for example. However, our most pressing need is to use what we already know about relieving suffering. The person in pain today does not have to wait for a better drug to be developed--he just needs someone to prescribe correctly what we already have! The person who wants to die at home needs no new device--she just needs the community to figure out how to get supportive services to her at home. As the report *Approaching Death* from the Institute of Medicine recommended, "Physicians, nurses, social workers, and other health professionals must commit themselves to improving care for dying patients and to using existing knowledge effectively to prevent and relieve pain and other symptoms."

Indeed, what we most need is to learn how to ensure quality, reliability, and efficiency. That takes public and professional education, changes in services and arrangements, and higher standards. In our book for the public, *The Handbook for Mortals*, for example, we instruct patients and families on how to get good pain management by giving them a comforting mini-course on what to expect, how to ask questions, how to counter errors, and how to adjust medications. In just a dozen pages, with sample words to try out, patients can know enough to start to act as colleagues in managing their situation. We also help patients understand how to make advance care plans that make a difference, how to navigate the care system, and how to pay attention to family and spiritual issues.

Some of our problems as a community arise from the persistence of old conceptions and categories. While we are still learning how to think about our new circumstances at the end of life, we tend to use words and categories that come from an earlier and outdated perspective.

Much of our language about death and dying conceives of palliative or “end of life” care as a turning away from conventional care. People presumed that a patient would generally get “aggressive treatment” until that was ineffective, and then the patient would turn to “hospice care,” or “palliative care,” which included only symptomatic treatment. This mental model of a transition from one kind of care to another works only if the patient really “turns a corner” and ordinary medical treatment becomes mostly worthless to the patient. This pattern *does* happen with many patients with certain cancers. They go along for many months functioning well and comfortably. Then, cancer overwhelms their bodies; they lose weight, take to bed, develop many more symptoms, and die within a few weeks or months.

Trajectory of Dying for Lung Cancer or CHF



Most of us will not die this way. Instead, we will be disabled for many months or years by diseases such as heart disease, emphysema, stroke, dementia, and even cancers like breast cancer and prostate cancer. Along the way, we will have episodes of serious complications. Any one of these episodes can cause death, and one of them will—but we will not know which one until it is upon us. In other words, most people die of a serious chronic disease, in a week that started just like many other weeks. People now die “suddenly” of long-established illness.

As a society, we are just beginning to learn how to arrange care to serve this population. Hospice is our most dramatic and useful innovation in end of life care. More than half of cancer patients who die while covered by Medicare use hospice. They are treated to unusually

coordinated and comprehensive care, in general. Often, though, patients are not eligible for hospice, since their prognosis is too uncertain until just the last few days. They may not have skilled needs or be homebound, so they get no home care services. Yet, they are terribly sick and fragile. A major challenge for the first decade of this century is to learn to serve this large and growing population that was, until recently, just not apparent to us.

We do have evidence that care at the end of life is improving, and much is being done. I will leave it to my colleagues to tell you about the remarkable work of the Veterans Health Care System, the various organized efforts to educate professionals, and other initiatives. I will focus here on two endeavors—helping the public to learn how to manage end of life issues, and helping the professional care providers learn how to improve their practices.

Last year, about seventy friends of the Center to Improve Care of the Dying helped to produce *The Handbook for Mortals: Guidance for People Facing Serious Illness*. The book offers straightforward common sense advice, helps people to take charge of the end of life, and includes poetry and metaphor to help make sense of the situation as well. Over and over, the response from patients and families has been that the book “gave us the words.” We seem to be so unfamiliar that we simply do not know how to talk about our experiences or to make sense of them. The tables here show two examples of helpful advice to the public from *the Handbook for Mortals*.

## Words to Try: For Families, Talking with a Sick Person

When you think you want to say: Try this instead:

- |   |  |
|---|--|
| <ul style="list-style-type: none"> <li>• Dad, you are going to be just fine.</li> <li>• Don't talk like that! You can beat this!</li> <li>• I can't see how anyone can help.</li> </ul> | <ul style="list-style-type: none"> <li>• Dad, are there some things that worry you?</li> <li>• It must be hard to come to terms with all this.</li> <li>• We will be there for you, always.</li> </ul> |
|---|--|

## Getting the Most Out of Each Visit With Your Doctor

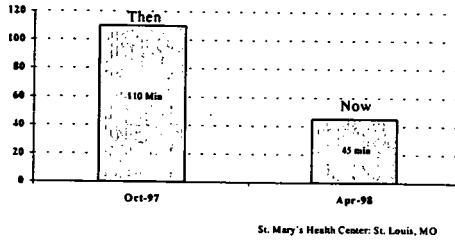
1. Prepare a list of questions and concerns that you want to discuss
2. Consider bringing a family member or friend to help you
3. Bring all of your medicines or a list of them all
4. Set your priorities for the doctor's time
5. Be honest
6. Take notes and repeat what the doctor tells you—in your own words
7. Make contingency plans.

We learned a great deal from producing the *Handbook*. Mainly, we learned that patients and families are desperate for information and insight. Our culture has kept serious long-term illness hidden away. Television shows almost no stories of people living with serious and progressive disabilities and illnesses. So people first encounter these situations as older adults with no experience. I have had so many patients and families turn to me and say something like, “What do I do now?” Over and over, I find that they are not just looking for friendly advice – they really have no idea what people do, or should do, when faced with serious chronic disease. Perhaps federal entities have a role in meeting this need. For example, Medicare’s existing efforts to improve beneficiary information could address serious chronic illness and end of life issues. Public information from the Health Resources and Services Administration and the Centers for Disease Control and Prevention could likewise address these issues.

We also have learned from working with the Institute for Healthcare Improvement and teams from nearly one hundred provider organizations that wanted to improve end of life care. Mostly, we learned that improvements can be made—quickly and effectively. Nearly every team that stayed with the job for a few months made major improvements in something that

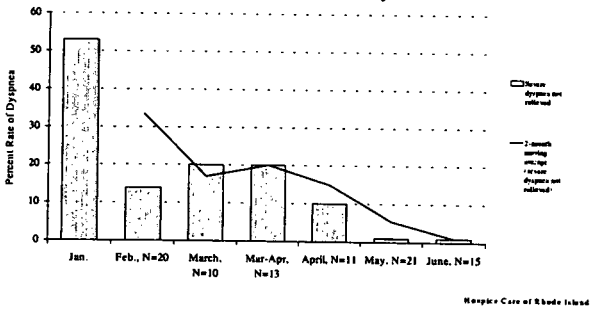
matters to patients—within this time. For example, one hospital cut the time a patient had to wait for better pain medication in half.

### Time Elapsed (in minutes) From Orders to Administration



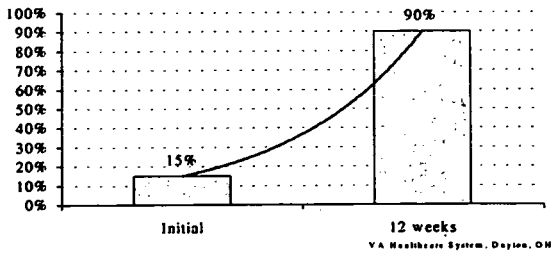
Another program nearly eradicated serious shortness of breath.

### Rates of Dyspnea Not Relieved by End of Shift



One program showed that advance planning could cut the rate of frightening episodes to one-quarter of the usual rate. One Veterans Medical Center actually increased the rate of written advance care plans for patients with serious chronic illnesses from 15 % to 90%.

## Advance Care Planning Documentation



Nearly all of the programs that worked with heart and lung failure patients cut their rate of hospitalization by 20-50%. One program had trained nurses available to come to the patient's home within half an hour to help with an exacerbation of symptoms. This cut the rate of using emergency rooms to well under half of the previous rate.

How did our collaborating teams get these astonishing results? By using rapid quality improvement methods, which are now well-proven enough that they should be part of the training of professionals. HRSA and AHRQ could be asked to take a role in implementing these strategies much more broadly. So often, what gets in the way of reliably good care is a practice that has become anachronistic, but has not been recognized as such. A caring team that tries out changes fairly quickly finds avenues to get things done right, and efficiently. What is needed to fix a problem in one organization will frequently not be the same as what is needed somewhere else. What we have found, though, is that improvements are possible virtually everywhere.

Some particularly challenging problems will require new insights. Our Center is now working with a few places in the country that are aiming at regional excellence. Think about your own health care—you can't always get what you need in just one care program, as programs are usually defined. At the end of life, this problem becomes exaggerated. Then, you

will usually need good hospital care, smooth transitions to home care and hospice, good nursing homes, and readily available medications. We have found it illuminating to think about what it would take to make care reliable enough that patients can count on it. We have translated this idea into “Promises for Patients,” a set of promises that a good care system should be able to make—from onset of serious illness through to death (even if that runs many years). To make these promises, a physician or nurse would have to know that every part of the care system is reliable. Figuring out how to deliver on that is a major challenge for the next few years.

*Making Promises: A Vision of a Better System*

1. *Good Medical Treatment*
2. *Never Overwhelmed by Symptoms*
3. *Continuity and Comprehensiveness*
4. *Planning Ahead, No Surprises*
5. *Customized Care, Reflecting Your Preferences*
6. *Family is Part of Care*
7. *Make the Best of Every Day*

Of course, Medicare has a role in making excellent care widely available. Serious chronic illness has come to be concentrated in old age—now 75% of us die past 65 and covered by Medicare. Medicare provides reasonably well for procedures and hospitalizations, but mostly does not pay for patient/family education for self-care, medications, caregiver supports, or continuity. This pattern is almost perfectly mismatched with the needs of those who face dying. We could really benefit from a few years of substantial innovation and evaluation, learning how to build a rather different care system that was tailored to our new demographics.

Indeed, we only have a few years to learn. The numbers of people who are very sick at the same time will continue to rise for the next three decades, eventually tripling from the present rates. If we continue to do no better than we do now, the suffering will be overwhelming, and the costs will be crippling. If we learn to do better and to deploy our knowledge effectively, we could instead have an end of life that is comfortable and meaningful in a care system that is sustainable.

This fall promises to see a substantial increase in public attention to end of life issues. Bill and Judith Moyers will have a four-part series on PBS in early September. Many magazines and newspapers are planning stories loosely linked to this, including a multi-page insert in *Modern Maturity*. The nation's public libraries and hospices, for example, will be sponsoring a large number of community meetings on the topics raised. The National Coalition for Health Care and The Milbank Foundation will be releasing separate reports on what can be accomplished by provider organizations today. Improving end of life care may well be a very important issue this fall! Our group has established a website that will help those from provider organizations who might be interested in improvement: <http://www.medicaring.org>. We will provide initial information and guidance, refer to others who offer help in specific areas, and offer follow-up information as opportunities arise. We will help your offices to answer public inquiries as well, including by putting you in touch with the growing array of concerned experts and proven improvement activities.

Significant and enduring improvement is within our grasp. All it takes is leadership and vision and a lot of hard work. The Congress, our country's leaders, could provide the leadership and vision. We could initiate substantial efforts to learn together how to serve those coming to the end of life. All of us have a stake in this, and all of us will reap the benefits of learning to do it right!

*To improve the end of life for patients and families, Congress should:*

- Encourage innovation in providing services, and insight as to what will work
- Support learning, professional and public
- Evaluate policies, existing and proposed, by effects on those with serious chronic illness, and their caregivers
- Aim to develop coherent, efficient, and effective strategies to serve this population -- within a few years\*

**Attachments:**

- Promises to patients
- Twenty things clinicians could do
- Getting started—improvement activities for providers
- The Agitator's Guide



## *Making Promises: A Vision of a Better System*

There are probably a number of ways to construct a vision of a better care system. One that has a special power is to think through the image of a single health care provider talking with a single sick and frightened patient and trying to imagine what that provider could promise — in a care system that really worked the way it should. For patients with advanced stages of serious illnesses, it is just not possible to promise cure or restoration of health. What would matter to such a patient? Here are the seven promises that really seem to make a difference. In each case, there is a short name for the promise, its core statement, and a few examples of what it might mean to put practices in place to deliver on that promise.

1. *Good Medical Treatment: You will have the best of medical treatment, aiming to prevent exacerbation, improve function and survival, and ensure comfort.*
  - *Patients will be offered proven diagnosis and treatment strategies to prevent exacerbations and enhance quality of life, as well as to delay disease progression and death*
  - *Medical interventions will be in accord with best available standards of medical practice, and evidence-based when possible*
2. *Never Overwhelmed by Symptoms: You will never have to endure overwhelming pain, shortness of breath, or other symptoms.*
  - *Symptoms will be anticipated and prevented when possible, evaluated and addressed promptly, and controlled effectively*
  - *Severe symptoms—such as shortness of breath—will be treated as emergencies*
  - *Sedation will be used when necessary to relieve intractable symptoms near the end of life*
3. *Continuity, Coordination, and Comprehensiveness: Your care will be continuous, comprehensive, and coordinated.*
  - *Patients and families can count on having certain professionals to rely upon at all times*
  - *Patients and families can count on an appropriate and timely response to their needs*
  - *Transitions between services, settings, and personnel are minimized in number and made to work smoothly*

4. *Well-Prepared, No Surprises: You and your family will be prepared for everything that is likely to happen in the course of your illness.*
  - *Patients and families come to know what to expect as the illness worsens, and what is expected of them*
  - *Patients and families receive supplies and training needed to handle predictable events*
  
5. *Customized Care, Reflecting Your Preferences: Your wishes will be sought and respected, and followed whenever possible.*
  - *Patients and families come to know the alternatives for services, and expect to make choices that matter*
  - *Patients never receive treatments they refuse*
  - *Patients usually live out the end of life at home, if they want to do so*
  
6. *Use Of Patient And Family Resources (Financial, Emotional, and Practical): We will help the patient and family to consider their personal and financial resources and we will respect their choices about the use of their resources.*
  - *Patients and families will be aware of services available in their community and the costs of those services*
  - *Family caregivers' concerns will be discussed and addressed. Respite, volunteer, and home aide care will be part of the care plan when appropriate.*
  
7. *Make The Best Of Every Day: We will do all we can to see that you and your family will have the opportunity to make the best of every day.*
  - *The patient is treated as a person, not a disease, and what is important to the patient is important to the care team*
  - *The care team responds to the physical, psychological, social, and spiritual needs of patient and family*

*Families are supported before, during, and after the patient's death*

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## *20 Improvements in End of Life Care - Changes Clinicians Could Do Next Week!*

Donald M. Berwick, MD, Institute for Health Care Improvement and Joanne Lynn, M.D., Center to Improve Care of the Dying

1. Ask yourself as you see patients, "Would I be surprised if this patient died in the next few months?" For those "sick enough to die," prioritize the patient's concerns - often symptom relief, family support, continuity, advance planning, or spirituality.
2. To eliminate anxiety and fear, chronically ill patients must understand what is likely to happen. When you see a patient who is "sick enough to die"--tell the patient, and start counseling and planning around that possibility.
3. To understand your patients, ask;
  - (1) "What do you hope for, as you live with this condition"
  - (2) "What do you fear?"
  - (3) It is usually hard to know when death is close. If you were to die soon, what would be left undone in your life?"
  - (4) "How are things going for you and your family?" Document and arrange care to meet each patient's priorities.
4. Comprehensive and coordinated care often breaks down when providers don't have all the facts and plans. The next time you transfer a patient or a colleague covers for you, ask for feedback on how patient information could be more useful or more readily available next time.
5. Unsure how to ask a patient about advance directives? Try: "If sometime you can't speak for yourself, who should speak for you about health care matters?" Follow with:
  - (1) "Does this person know about this responsibility?"
  - (2) "Does he or she know what you want?"
  - (3) "What would you want?"
  - (4) "Have you written this down?"
6. To identify opportunities to share information with patients and caregivers, ask each patient who is "sick enough to die:" "Tell me what you know about \_\_\_\_\_(their disease)." Then: "Tell me what you know about what other people go through with this disease."
7. Most internists' practices have educational handouts on heart failure, COPD, cancer, and other fatal chronic illnesses to give to patients. Read them - if your handouts do not mention prognosis, symptoms, and death exchange them for ones that do. Perhaps make The Handbook for Mortals and other resources available to your patients.
8. Some patients and their families are getting most of their information from the Internet. Log onto a patient-centered Internet site about an eventually fatal chronic illness to learn what is of interest to patients and families.
9. Is coordinating the care of your chronically ill patients taking up too much of your time? Call a local advocacy group (American Heart Assoc., American Cancer Society, etc.) for help, or consult with a care management service.

10. Discussing and recording advance directives with all your patients may take a while. How many patients over the age of 85 do you have? Start making plans with them. Expand to all who "are sick enough to die."
11. Use each episode in the ICU or ER as a "rehearsal." Ask the patient what should happen the next time. Be sure the patient has all necessary drugs at home and knows how to use them. Can you promise prompt relief from dyspnea near death? Tell the patient and family what's possible, and make plans together.
12. Ask your next patient who is "sick enough to die" whether anything happened recently regarding their medical situation for which they were unprepared. Work to anticipate the expectable complications and to have plans in place.
13. Since meperidine (Demerol) is almost the only opioid which has toxic metabolites and thus is contraindicated for chronic pain, banish meperidine from your prescribing and from the formularies where you work.
14. Very sick people will often be most comfortable at home or in nursing homes. Identify programs that are good at home care, send patients to those quality services, and work with them to fill the gaps your patients encounter.
15. Feedback on performance guides improvement. Find the routine surveys, administrative data, and electronic records that record symptoms, location of death, unplanned hospital or ER use, family satisfaction after the death, and other outcomes. Set up routines to get feedback on performance and improvement every month.
16. Except in hospice, most families never hear from their internist after a death. Change that! Make a follow-up phone call or set a visit to console, answer questions, support family caregivers, and affirm the value of the life just recently ended. At least, send a card!
17. Working with very sick patients who die is hard on caregivers. Next week - and every week - praise a professional or family caregiver who is doing a good job.
18. We can't really change the routine care without changing Medicare. Contact your congressional representatives to ask for hearings, demonstration programs, research, and innovation to improve the Medicare program.
19. Some of our language really does not serve us well. Never say "There's nothing more to be done," or "Do you want everything done." Talk instead about the life yet to be lived, and what CAN be done to make it better (or worse).
20. Patients and families need to be able to rely upon their care system. Consider what you can PROMISE on behalf of your care system - pain relief, family support, honest prognosis, enduring commitment in all settings over time, planning for complications and death, and so on. Pick a promise that your patients need to hear and start working with others to make it possible to make that promise! Quality improvement strategies work.

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*To Providers: For those who help provide care for the very sick and want to be part of making the care system more reliable and capable*

We all have to be part of the solution—we have all been part of the problem!  
It is time to get reforms underway!

**Here are some pointers for starting out.**

1. Commit yourself to helping to build a care system that your sickest patients and their families can count on. It's an aim worth achieving!
2. Start on improving something right away. Some little thing can be done today, or this week.
3. Use the expertise that's there for you – the accompanying list is a good start. An updated list with more information and hyperlinks is at [www.medicaring.org](http://www.medicaring.org).
4. Target all patients "sick enough to die," not just those "almost certain to die soon."
5. Make sure that every patient with an eventually fatal illness comes to know about his or her prognosis and gets help making plans for complications and eventually death.
6. Consider families and caregivers – what could be done to ease their fears and burdens?
7. Be sure that patients never have to go for long with serious symptoms – regular assessments and rapid response are key
8. Build in assessment – know whether your organization is improving and share success stories!

**DO**

- find something to start on this week
- work on what inspires you
- find a team that shares your interests
- try out ideas on small numbers

**DON'T**

- study the problem without starting changes
- assume problems are someone else's
- insist on more personnel or funds before starting
- ignore public opinion

***Some specific changes you might try:***

**For relieving chronic pain** – regular assessments, rapid response, no meperidine

**For advance care planning** – trigger review at transitions between programs, ensure availability

**For palliative care program** – develop local experts, engage community, measure effects early

**For family support** – plan for time near death, counsel about finances, phone call after death

**For patient/family self-care** – curriculum for home care, classroom sessions, rehearsals

**For regional collaboration** – regional guidelines on pain and advance planning

(adapted from Lynn J, Schuster JL, Kabcenell A, *Improving Care for the End of Life: A Sourcebook for Health Care Managers and Clinicians*, Oxford University Press, 2000)

*"The Agitator's Guide: Twelve Steps to Get Your Community Talking about Dying"*

1. *Call Your Local Paper's Obituary Writer.* Ask him or her to say something about how a person lived during the last years or months--what did he or she do? What did the family do?
2. *Write a Letter to Your U.S. Representatives and Senators.* Urge them to have the Health Care Financing Administration sponsor demonstration programs in end-of-life care.
3. *Call or Write Your Local Chamber Of Commerce.* And talk to your employer, too, about ways to support family caregivers and protect their jobs during leave.
4. *Talk To Local Churches or Civic and Volunteer Groups.* Together, you can support those who are dying and their families through visits, transportation, meals, and even prayer groups.
5. *Write Letters to Your Local Media.* When articles or programs run about aging or death and dying, note your appreciation, point to gaps in coverage, and counter misleading anecdotes.
6. *Talk To Your Doctors about Advance Care Planning and Pain Control.*
7. *Ask For A Report Card.* If your community has a comparison list of health plans, press the group to include something about caring for people who are very sick and likely to die. Do plans cover hospice? What do families say about symptom control? Continuity of and access to care?
8. *Ask Local Media To Develop A Series on How Serious and Eventually Fatal Illness Affects People in Your Community.*
9. *Push Your Local Health Care System--Even If it's Only One Doctor's Office--To Get Involved In Quality Improvement Efforts.*
10. *Write to Your Favorite Television or Radio Show.* Ask them to include stories about--or even just mention, people who are facing serious illness and death, and how they and their loved ones manage.
11. *Keep Pace with What's Going on In the Field.* Americans for Better Care of the Dying advocates improved care of the dying and public policy that promotes such care. Our monthly print and electronic newsletter, *The Exchange*, reports on the field.
12. *Read Handbook For Mortals: Guidance For People Facing Serious Illness.* Donate copies to local churches, hospitals, or hospices--or give them to friends who need guidance and support.

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The CHAIRMAN. Thank you. Quite an ending.  
Dr. Tulsky.

**STATEMENT OF JAMES A TULSKY, M.D., ASSOCIATE DIRECTOR, DUKE INSTITUTE ON CARE AT THE END OF LIFE; ASSOCIATE PROFESSOR OF MEDICINE, DUKE UNIVERSITY; DIRECTOR, PROGRAM ON THE MEDICAL ENCOUNTER AND PALLIATIVE CARE, DURHAM VETERANS ADMINISTRATION MEDICAL CENTER, DURHAM, NC**

Dr. TULSKY. Good afternoon. I take care of dying patients, direct a research program to improve doctor-patient communication in palliative care, and train health professionals. I am grateful to the committee for bringing this issue to the public consciousness. Patients facing life-threatening illness expect compassion, counseling and care. However, as we have just heard, many physicians never discuss with patients the realities of their illness or help them prepare for the challenges they will face.

Delivering bad news or discussing a person's impending death is not an in-born skill. Health-care providers must be trained to communicate. Unfortunately, professional schools have not kept pace with the public's expectations. We have audiotaped over 150 actual conversations between doctors and patients at the end of life, and found that physicians often do not provide sufficient information to allow patients to make informed decisions.

The potential outcomes of treatment are rarely discussed, conversations are brief and physicians frequently ignore the emotional impact of these discussions. Medical schools do not teach these skills. A recent study found that, "Current training in end-of-life care is inadequate. There is little attention to home care, hospice and nursing home care, and, "I emphasize," role models are few."

We surveyed physicians-in-training and learned that although they have frequent conversations with dying patients, they infrequently observed more skilled physicians having such conversations and are rarely observed themselves. One-third had never been observed by a more-experienced physician while discussing end-of-life treatment preferences. If role models were present, the education would follow. The problem is not confined to medical schools. The experienced clinician who opens a typical medical or nursing text is unlikely to find much help in caring for a dying patient. Last year, a study of the major textbooks revealed they were missing nearly 60 percent of the content necessary to manage a dying patient's distress. Reading some of these books, one might think that no one dies from congestive heart failure, colon cancer or dementia.

Three years ago, the Institute of Medicine recommended major changes in medical education. I will mention a couple of interesting programs with which I have had direct experience. Many other wonderful initiatives exist.

Four months ago, we established the Duke Institute on Care at the End of Life to improve the experience of dying patients through interdisciplinary scholarship, teaching and public outreach. The institute is unique in that it is based in the divinity school, not the medical center. In a recent survey of 1,000 seriously ill patients and bereaved family members, we learned that, after pain control,

finding spiritual peace was the primary concern for those facing death.

By establishing the institute in a school whose focus is theological and pastoral education, we ensure that this voice gets heard. Yet the medical school is only a block away, and institute faculty are drawn from all corners of the university, representing medicine, theology, nursing, social work, ethics and the social sciences. Initial programs have included a symposium on access to care, an educational retreat for health care providers, a chaplain residency focused on the care of dying patients and several new research projects. Next month, we will be hosting a day-long training for pastors, chaplains and lay leaders to help equip them to facilitate a dialog like this one about death and dying in their faith communities. Our goal is to integrate and improve the medical and spiritual care of patients.

What about efforts to improve communication skills? Several years ago, I took care of a man in the hospital with terminal lung cancer, who had been hooked up to a mechanical ventilator. He and his wife knew that he was dying and he had no desire to spend his last days dependent on a life-support machine. However, when he became short of breath, his wife had been asked, "Do you want us to do everything for your husband?" She had given the only response possible for a loving spouse, and answered yes. Imagine instead if the doctor had said, "This must be a terrible time watching your husband die. Let's talk about how we can make things more comfortable for you and him." This wife would have made very different treatment choices and her husband's last hours would have been less burdensome and more meaningful.

Several of us have created and disseminated a model for communication in which clinicians address a patient's and family's emotion and never talk about "doing everything" or "nothing." We use role play, patient actors and real patient volunteers to practice and observe the methods that work best, and our preliminary findings show that this training works. These programs are part of what needs to be a broad national strategy. Our medical trainees must be taught basic pain and symptom management. Excellent communication skills must become a core competency for physicians and not a pleasant surprise for patients.

We must develop centers of excellence to promote the basic principles and practices of palliative care. Can we achieve this agenda? Yes, but only with ongoing support. All of the programs I have described have been funded by private foundations and, as priorities change, their security is at risk. Government has traditionally assumed responsibility in this area. Federal mechanisms already exist to support palliative care training.

For example, HRSA, the VA, or the NIH could create fellowships to train future leaders in palliative care. The National Cancer Institute could support palliative care training in its cancer centers. These relatively small investments would generate impressive returns. When we die, each of us hopes to be cared for by a health professional who is well-trained to meet our complex needs. Currently, this is not guaranteed, although the tremendous progress of the past few years inspires optimism.



If government becomes a partner in these innovations, there is no limit to the improvements we can make for dying patients and their families.

Thank you.

[The prepared statement of Dr. Tulskey follows:]

Program *on the*  
Medical Encounter  
& Palliative Care

James A. Tulsy, M.D.  
Director

TESTIMONY  
BEFORE THE SENATE  
SPECIAL COMMITTEE ON AGING

JULY 17, 2000

JAMES A. TULSKY, MD

Director, Program on the Medical Encounter and Palliative Care  
VA Medical Center, Durham, NC

Associate Professor  
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An affiliate of the Veterans Affairs Center for Health Services Research and Development in Primary Care and Duke University Medical Center



Good afternoon, my name is Dr. James Tulsky. I am Director of the Program on the Medical Encounter and Palliative Care at the Durham VA Medical Center, and Associate Professor of Medicine at Duke University. In addition, I help lead the newly established Duke Institute on Care at the End of Life. In these roles, I take care of patients facing life threatening illness, teach physicians and other health professionals about palliative medicine, and conduct research to improve doctor-patient communication and the care of dying patients. I am extremely grateful to the Committee for holding these hearings. In my testimony, I would like to focus on the difficulties we observe when doctors communicate with dying patients, describe several exciting new programs to address these and other shortcomings in care at the end of life, and identify the need to train more health professionals with expertise in palliative care.

In 1961, only 10% of doctors preferred to tell their patients that they had a diagnosis of cancer. Even fewer discussed with them the fact that they might die. Today, only the rare physician does not share the diagnosis of cancer with his or her patients. However, many still never mention the likelihood that this disease will lead to their death.

The fact that norms for disclosure about cancer have changed so dramatically attests to the success of a movement that has placed patients' rights and autonomy in the forefront of the public's conscience. However, the fact that many patients today will never hear a discussion of the prognosis of that cancer is a tragedy. And even when patients are told their diagnosis or prognosis, the quality of the communication may be so poor that the patients' needs are not met.

We have an intelligent and demanding public that expects to receive as much information as possible, in a manner that is sensitive, clear and compassionate. However

medical education has not kept up with the public's expectations and many physicians are simply ill-equipped to communicate effectively about these issues. Few among us, including physicians, are born knowing how to deliver tragic news or to discuss a person's impending death. Unfortunately, many people attend medical school and are never taught these skills.

Let me give you some examples of the communication problems to which I am referring. We audio taped over 150 actual conversations between doctors and patients about decisions at the end of life, and learned that the quality of communication is sorely lacking. We found that physicians often did not provide sufficient information to allow patients to make an informed decision. The potential outcomes of treatment, an integral component of informed consent, were rarely discussed. When asking patients whether they would want to undergo resuscitation if their heart or lungs failed, only 13% of physicians mentioned the patient's likelihood of survival after resuscitation. We found that conversations about advance directives averaged less than six minutes each and physicians spoke two-thirds of this time. They used vague language, did not explore patients' values and, for the most part, ignored the tremendous emotional impact of these discussions on patients. I encourage you to visit the website of the Program on the Medical Encounter and Palliative Care (see bottom of cover page), where you can download a reenactment of one of these actual conversations between a doctor and patient about end-of-life treatment choices. It is eye-opening and will give you a first hand feel for the challenges we must assume to improve communication.

What is the current state of medical education about end of life care that has led to such deficiencies? A recent review from the Journal of the American Medical

Association stated that “while nearly all medical schools offer some formal teaching about end-of-life care, there is considerable evidence that current training is inadequate, most strikingly in the clinical years. Curricular offerings are not well integrated; clinical experiences are mostly elective; there is little attention to home care, hospice, and nursing home care; and, **role models are few.**” One of our goals for improving this system must be to create professionals trained in palliative care who can pass on their knowledge to students and other clinicians.

We surveyed young physicians at a major academic medical center and learned that although they have conversations with dying patients on a weekly or even daily basis, they have infrequently had the opportunity to observe more skilled physicians talk with their patients. In fact, one third had never been observed by a more experienced physician while discussing end-of-life treatment preferences with a patient or family member. Health care skills are taught predominantly using the apprenticeship model, or “see one, do one, teach one,” as the students themselves refer to it. In truth, one needs to see and do many more prior to being well trained, however, the general model is successful and has led to highly skilled clinicians. Unfortunately, communication skills are not regarded with the same scrutiny that we use for other procedural skills and oversight is insufficient. We must recognize that one can hurt a patient with misplaced words just as severely as one can hurt a patient with a misplaced scalpel. Research shows that poor communication leads to worse patient outcomes.

Clearly, we have a problem in medical education. But even the experienced clinician who turns to a typical medical or nursing text is unlikely to find much help in caring for a dying patient. Last year, a study of the major medical textbooks revealed that

information on end of life care was sorely lacking. These textbooks were missing nearly 60% of the appropriate content that would help one manage the physical, psychological and spiritual distress of the dying patient. Even oncology textbooks were missing this information. After reading some of these chapters, one might conclude that people simply don't die from congestive heart failure, colon cancer or dementia!

Although nursing has frequently been ahead of medicine in this regard and, as a profession, has spearheaded the development of hospice care, nursing textbooks don't fair much better. A similar review of nursing textbooks also found striking deficiencies in the content related to the care of dying patients. The good news is that both of these projects have led to collaborative efforts with the textbook editors to include more content on end of life care.

Clearly, an extremely high priority for improving the care of dying patients must be the education of physicians and other health care providers. The Institute of Medicine highlighted this need in its 1997 report on *Improving Care at the End of Life*. One of the Institute's primary recommendations was that "educators and other health professionals should initiate changes in undergraduate, graduate, and continuing education to ensure that practitioners have relevant attitudes, knowledge, and skills to care well for dying patients."

The good news is that the last few years have seen a proliferation of efforts to accomplish these goals. I will accent several of these initiatives that are particularly interesting and with which I have direct experience; they are only a small sample of the many innovative programs that have recently emerged. Also, as another witness will

represent the Department of Veterans Affairs, I will not address the truly remarkable commitment that agency has made to advance this agenda.

Four months ago we established the Duke Institute on Care at the End of Life. Made possible by a generous gift from the Foundation for End of Life Care, VITAS Healthcare and other donors, the Institute's mission is to improve care at the end of life through interdisciplinary scholarship, teaching and public outreach. What makes this effort unique is that the Institute is based in the Divinity School at Duke, rather than the Medical Center. To some, this may seem odd. However, our recent research would suggest that this may help us respond to what many our patients are looking for.

We conducted a national survey of 1,000 seriously ill patients and recently bereaved family members. We learned that after pain control, finding spiritual peace was the primary concern for those facing death. In fact, these two goals were of nearly equal importance to patients and families. Spiritual peace was more important than having treatment choices followed, having one's finances in order or dying at home!

If spiritual needs of patients at the end of life are paramount, then what better way to ensure that this voice gets heard than to establish an Institute on Care at the End of Life in a school whose focus is theological education and the training of pastors? At Duke University we can do this and remain a one block walk from the medical school. The faculty of the Institute are drawn from all corners of the University, and our programs are truly interdisciplinary. The Institute's director is a psychiatrist and theologian with a primary appointment in the Divinity School; I am an internist based in the Medical Center; and we have representatives from nursing, social work, ethics, counseling, and the social sciences. Some of our initial programs have included a highly successful

symposium on Access to Care at the End of Life, an intensive two day palliative care educational retreat for Duke health care providers, a pastoral care residency focused on the care of dying patients, a visiting scholars program and several new health services research projects. In the fall, we will be holding a symposium to provide training for pastors, chaplains and lay leaders so that they are equipped to facilitate a dialogue about death and dying in their faith communities. As a measure of the interest in this area, this program is already oversubscribed. We have an ambitious agenda ahead of us, as we try to find ways to truly integrate and improve both the medical and spiritual care of patients.

I would also like to mention efforts to improve physician communication skills. The following story illustrates what we have learned about the power of words and what we need to teach. Several years ago I arrived in the emergency room to admit a patient to the hospital with widespread, advanced lung cancer, and found that he had been hooked up to a mechanical ventilator. I wondered why this had been done, given that the patient and his wife knew that he was dying and had not intended for him to spend his last hours or days dependent on life support machines. I discovered that when he arrived in the emergency room short of breath, the patient's wife had been asked, "Do you want us to do everything for your husband?" She had been forced to give the only response that a loving spouse can give and answered "yes." Instead, if that doctor had said, "This must be a terrible time watching your husband die. Let's talk about how we can make things most comfortable for the two of you," this wife would have made very different choices about the treatments he would receive, and his last hours would have been less burdensome and more meaningful. What if we could teach clinicians to instinctively



address patients' and families' emotions, rather than talking about doing "everything" or "nothing?"

Through a variety of programs, we have found ways to disseminate this different model for communication. Last month I spent a week in Rochester, NY with 80 other doctors, nurses and social workers at a meeting of the American Academy on Physician and Patient, where we focused exclusively on improving communication at the end of life. We used role play, standardized patients (patient-actors), and real patient volunteers to practice and observe the methods that work best. Through focused and supervised practice, clinicians learned about themselves, their own reactions to patients, and how to communicate most effectively. They learned to elicit concerns and to demonstrate their empathy for the patient.

At the Durham VA and Duke University Medical Centers we have been conducting a palliative care education program for several years called PREPARE, Program on Resident Education to Promote Awareness and Respect at the End-of-Life. In this project, funded by the Robert Wood Johnson Foundation, we bring the medical residents to an intensive retreat on palliative care, during which they learn pain and symptom control and also learn how to talk with patients at the end of life (see attached retreat agenda). Another project, also supported by the Robert Wood Johnson Foundation, is attempting to disseminate this type of education by training faculty from medicine residency programs across the nation to teach palliative care skills. This training has been accepted, in part, because of the commitment of the American Board of Internal Medicine to making palliative care a core competency for practicing internists.

Many excellent programs are clearly surfacing to educate health care providers about pain and symptom control, communication with patients and attending to psychosocial and spiritual concerns. These are the beginning of what needs to be an even broader agenda. All medical trainees must be taught the basics of pain and symptom management. Excellent communication skills must become a core competency for physicians, and not a pleasant surprise for patients. We must develop multiple centers of excellence to promote and teach the best principles and practices of palliative care.

Is this agenda achievable? Yes, but only with ongoing support. All of the programs I have described have been funded by private foundations that have engaged this issue in an effort to create a cultural shift in the way we view death and dying. The priorities of the foundations will eventually change and I predict that many will withdraw their support for palliative care. Government must step in and become a leader in the areas where it has traditionally assumed responsibility. Mechanisms already exist for the federal government to support the training of experts in palliative care. For example, the Health Resources and Services Administration (HRSA), the Department of Veterans Affairs, or the National Institutes of Health could create fellowships to train future leaders in palliative care. The National Cancer Institute could require and support cancer centers to offer palliative care clinical services and training programs. These are relatively small interventions that could result in potentially huge results.

Everyone in this room is going to die. And, when that time comes, we hope to be cared for by health professionals who are well trained to meet our complex needs and by a health care system that allows them to do so. Although the barriers can sometimes seem overwhelming, the tremendous progress we have made these past few years inspires

optimism. If the federal government becomes a partner in these innovations, there is no limit to the improvements we can make for dying patients and their families.

The CHAIRMAN. Thank you, Dr. Tulsy.  
Now one of my constituents, Linda Todd.

**STATEMENT OF LINDA TODD, R.N., DIRECTOR, HOSPICE OF SIOUXLAND; REGIONAL REPRESENTATIVE, BOARD OF DIRECTORS, NATIONAL HOSPICE AND PALLIATIVE CARE ORGANIZATION, SIOUX CITY, IA**

Ms. TODD. 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 the Director of Hospice of Siouxland in Sioux City, IA. I also serve on the Board of Directors for the National Hospice and Palliative Care Organization.

There is a great deal of pride in health-care services that are offered in Sioux City IA. We have a trauma center, a burn unit, a regional cancer center, a heart program; a full array of health-care services, and yet our health-care system failed a patient and her family in the last months of her life, not because of our expertise or technology, but rather because of the lack of recognition of end-of-life care.

Shelly Twiford came to talk to me after the death of her mother. The overriding question was how did a hospice nurse know in a few minutes that her mother was dying and no one else knew? As I listened to her story, I was overwhelmed with the experiences of this family in which there seemed to be roadblocks every step of the way. One could sense the frustration and the chaos that this family experienced the last months of her mother's life.

As a provider of hospice for 15 years, I knew in my heart that hospice care could have made a difference for this family. With the assistance of the interdisciplinary team, physicians and nurses could have achieved pain control and symptom management. Home visits would have provided the necessary interventions to eliminate the need to transfer to the emergency room.

The social worker would facilitate discussions within the family and provide emotional support. A home-health aide could have provided the personal care for her mother and volunteers provided relief for the husband. The team would have assisted the family in understanding disease progression and knowing who and when to call for assistance.

The Medicare hospice benefit could have relieved the financial burden for the family. Shelly's mother would have been able to remain in her home to die, the same place that she had lived; and during bereavement, there would have been support to assist them with their grief, comfort from feeling that they had been able to respect her wishes, rather than feeling like they, as a family, had failed.

Recent research by the National Hospice Foundation showed that 25 percent of Americans are not likely to talk about impending death with their terminally ill parents, and fewer than 25 percent have put into writing how they want to be cared for at the end-of-life. Surprisingly, 90 percent of the respondents did not realize that Medicare pays for hospice. What will change these situations? Whenever you ask the question, it always comes back to the same response—education; education for consumers, for health-care professionals and physicians. Death is not failure. It is a part of life,

and until we embrace this thought and deal with the reality of death, people will continue to suffer.

There was a call to action in Sioux City, IA. An end-of-life task force was developed, representing professionals and community resources. The initiatives focus on advanced-care planning and education, including EPEC, Education for Physicians on End-of-Life Care. A major donor campaign has been launched to fund these initiatives and for the development of a palliative care service.

The National Hospice Foundation initiated a 3-year, multimillion dollar public engagement campaign for both the local and the national level. The campaign is designed to increase public awareness of hospice, foster discussions of end-of-life care, both on a public and personal level, and educate health-care professionals about hospice.

Campaign activity will focus on four elements: Public service announcements; online partnerships; medical education and hospice placement. The goals are to increase the number of people who select hospice as a preferred choice and to increase the length of time that patients have under hospice. Understanding of human suffering and how to help patients and their families facing end-of-life is essential. Terminally ill citizens and their families need a strong and consistent message that encourages the earliest consideration of hospice care and ensures access to our most vulnerable population.

The government needs to devote additional resources to further develop and advance the scientific understanding of pain and symptom management, and make the information available to health-care professionals and the general public. Our health profession schools need additional resources to develop and implement programs to provide ongoing education and training to their students in all phases of palliative care.

By enhancing the educational processes and focusing on public attention on the end-of-life issues, we will raise public awareness. It is time to examine how we care for our most vulnerable citizens, the terminally ill and their families, so they might enjoy living life to the fullest, even as they approach death.

Thank you.

[The prepared statement of Ms. Todd follows:]

**Testimony of Linda Todd**

**On behalf of the**

**National Hospice and Palliative Care Organization**

**Before the**

**Special Committee on Aging  
United States Senate**

**Hearing on**

**“The End of Life: Improving Care, Easing Pain and Helping Families”**

**July 17, 2000**

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 Sydenham, England. Her center

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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 a 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

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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



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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,

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- 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

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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.

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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

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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."

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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.

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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

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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.



The CHAIRMAN. Thank you, Ms. Todd.  
Now Dr. Rosenquist.

**STATEMENT OF RICHARD ROSENQUIST, M.D., MEMBER, VETERANS ADMINISTRATION NATIONAL PAIN MANAGEMENT STRATEGY COMMITTEE; DIRECTOR, PAIN MEDICINE DIVISION AND ASSOCIATE PROFESSOR, UNIVERSITY OF IOWA, IOWA CITY, IA**

Dr. ROSENQUIST. Mr. Chairman, members of the committee, ladies and gentlemen, my name is Richard Rosenquist and I am the Director of the Pain Management Clinic at the Veterans Medical Center in Iowa City, IA. I am also an Associate Professor of Anesthesia and the Director of the Pain Medicine Division in the Department of Anesthesia at the University of Iowa.

I am pleased to appear before you as a practicing physician at the Veterans Affairs Medical Center in Iowa City to discuss my involvement in the department's ongoing activities with regard to end-of-life pain management initiatives. Pain is a significant health-care problem in United States, and a substantial portion of the population is afflicted with pain each year.

Recent surveys and studies have determined that 20 to 30 percent of the population annually suffers from acute pain and/or chronic pain syndromes; further, the incidence and severity of pain increase with increasing age, resulting in a disproportionately large amount of chronic pain occurring individuals over 60 years of age.

Control of cancer pain remains a substantial unresolved problem in the United States. Fifty percent of all deaths in the United States are caused by cancer, with 75 percent of advanced cancer patients experiencing moderate to very severe pain. Traumatic injuries and surgical procedures result in 75 million episodes of acute pain each year, the majority of which are inadequately treated. Proactive, aggressive management of both acute and chronic pain is universally recognized as an essential component of health care. However, substantial evidence indicates that neither acute nor chronic pain is managed adequately within most U.S. health care systems.

This is due to a number of factors, including, No. 1, lack of knowledge regarding the availability of pain treatment by patients and their families; No. 2, lack of knowledge regarding their rights as a patient; No. 3, inappropriate fear of addiction on the part of patients, families and health care providers; No. 4, lack of knowledge on the part of health-care providers; No. 5, failure to routinely assess pain and effectiveness of therapy; and, No. 6, unavailability of state-of-the-art pain treatments on a consistent basis at all health-care institutions.

The importance of this issue has been recognized by the Veterans Health Administration, and we are now in the forefront of developing systematic solutions to this problem. As early as 1996, a VHA multidisciplinary pain committee was appointed to develop a national pain management strategy to ensure that appropriate acute and chronic pain care would be provided to veterans.

No generally applicable studies have been performed to determine types or incidence of pain in veterans. However, a conservative assumption can be made that veterans have at least the same

amount of pain as the general U.S. population. A greater instance of pain in veterans may be expected, due to the higher prevalence of trauma and psychological problems, both known to increase the incidence of pain and confound therapies.

As a result of the preliminary work of the National Pain Management Strategy Committee, a recommendation was made to appoint a permanent VHA Pain Advisory Committee to advance the pain management strategy. Former Undersecretary for Health, Dr. Kenneth W. Kizer, improved the comprehensive action plan and the importance of treating pain within the VHA was thus recognized in a formal way.

The first major initiative was to address pain as the fifth vital sign. This was formally announced and implemented in VHA in February 1999. This initiative has mandated that pain be assessed at the same time that routine vital signs such as heart rate, blood pressure, respiratory rate and temperature are taken and recorded in the patient record. The routine assessment of pain, along with ongoing development of guidelines regarding response to the pain score at the time of assessment will help drive improved treatment.

A subcommittee of the National Pain Management Strategy Committee has been charged with developing evidence-based guidelines to standardize and improve treatment of acute pain, cancer pain, and chronic pain. Concurrently, we have also begun to collaborate with the Institute for Health Care Improvement to improve delivery of pain and end-of-life care throughout the VHA.

The importance of education in making a change of this magnitude was immediately recognized by VHA. A toolkit has been developed as a means of helping the Veterans' integrated service networks implement pain as the fifth vital sign. In November 1999, a VA national leadership conference on pain management and end-of-life care was held. Finally, VHA recently funded 10 new pain residency positions to advance training in pain management and improve delivery of pain management services within our health care system.

I would like to make this a little bit more personal and share with you some of my own experiences at the VA Medical Center in Iowa City, IA. Since arriving in Iowa City in January, 1998 to assume the position of Director of the Pain Medicine Division at the University of Iowa, I have had the opportunity to make a number of changes and to expand the available services.

When I arrived, the pain clinic, which had been operating at the VA Medical Center in Iowa City, had been closed, and some patients were being cared for at the university Pain Medicine Clinic. I have had strong support from the Chief of Staff and the Chief of Anesthesia at the VA Medical Center in Iowa City. As a result, I have been able to reopen the Outpatient Pain Clinic and organize an inpatient acute pain service, providing epidural analgesia for post-operative pain control, with specialty call coverage 24 hours-per-day, 7 days-per-week. There remains a significant demand for pain services, and I hope that future expansion of services will allow us to meet a greater proportion of that demand.

I would also like to share with you an example of the type of patient encountered by our pain medicine team. A 75-year-old man recently presented to the Pain Medicine Clinic with a chief com-

plaint of severe left chest wall pain due to a tumor that was eroding through his ribs. At the time of his presentation, he was taking only 10 milligrams of Oxycontin every 12 hours and had no medications available for breakthrough pain.

He expressed concern about the use of narcotic pain medications and what they might do to him. His wife and daughter, who were with him, shared his concern. He made it clear that he had no misconceptions about what the future held for him, but that he did not want to suffer with pain for the remainder of his life. I explained to both the patient and his family the available options, including oral pain medications, nerve blocks and delivery of pain medication within the spinal fluid. I also emphasized the fact that the narcotic pain medications were a tool that was appropriate to use in his current situation, and that he should not fear addiction or a stain on his character for their use.

After some relatively minor dose adjustments, he returned for a follow-up visit and reported that he had excellent pain control without any significant side effects. This could have been done earlier and he could have experienced less pain overall; however, it would have required better knowledge on the part of the referring physician and an understanding of the issue of pain and its treatment during cancer by the patient. This is only one story, but it is repeated over and over again.

In conclusion, I would like to thank you for the opportunity to highlight an area of medical care that I believe to be vital, but often ignored. I would also like to emphasize the importance of your continued interest and support for education for the public at-large regarding issues of pain management—increasing education regarding pain during health care training and continuing medical education, and research to improve treatments and document their outcome. Improvements in these areas will have a significant impact on the delivery of health care and outcome throughout the United States.

Mr. Chairman, this concludes my opening remarks and I would be pleased to answer any questions that you or the members of the committee might have.

[The prepared statement of Dr. Rosenquist follows.]

Statement of

Richard Rosenquist, M.D.

Director, Pain Management Clinic

VA Medical Center, Iowa City, Iowa

Department of Veterans Affairs

and

Associate Professor of Anesthesia,

University of Iowa

End of Life Pain Management Initiatives

Before the

Special Committee on Aging

United States Senate

July 17, 2000

I am pleased to appear before you as a practicing physician at the Veterans Affairs (VA) Medical Center in Iowa City to discuss my involvement in the Department's ongoing activities with regard to end of life, pain management initiatives. Pain is a significant health care problem in the United States and a substantial portion of the population is afflicted with pain each year. Recent surveys and studies have determined that 20% to 30% of the population annually suffers from acute pain and/or chronic pain syndromes. Further, the incidence and severity of pain increase with increasing age resulting in a disproportionately large amount of chronic pain occurring in individuals over 60 years of age, 20% of whom require continual pain medication.

Control of cancer pain remains a substantial unresolved problem in the U.S. Fifty percent of all deaths in the U.S. are caused by cancer with 75% of advanced cancer patients experiencing "moderate" to "very severe" pain. Although methods to relieve pain can be effective in over 95% of patients when utilized, pain in most cancer patients is inadequately controlled because of low priorities, limited education of providers, and inappropriate attitudes towards opiate therapy. Traumatic injuries and surgical procedures result in 75 million episodes of acute pain each year, the majority of which are inadequately treated. Reducing frequency and controlling the level of pain is a health care challenge for all medical specialties.

The knowledge and techniques to control most pain are known, but they often are not applied effectively. Proactive, aggressive management of both acute and chronic pain is universally recognized as an essential component of health care; however, substantial evidence indicates that neither acute nor chronic pain is managed adequately within most U.S. health care systems. This is due to a number of factors including:

- 1) lack of knowledge regarding the availability of pain treatment by patients and their families,
- 2) lack of knowledge regarding their rights as a patient,
- 3) inappropriate fear of addiction on the part of patients, families and health care providers,
- 4) lack of knowledge on the part of health care providers,
- 5) failure to routinely assess pain and the effectiveness of therapy, and
- 6) unavailability of state-of-the-art pain treatments on a consistent basis at all health care institutions.

Since the root of this problem exists largely as an issue of education, it is critical that patients be informed of their right to pain relief and their fears of living and dying with severe suffering due to pain be allayed. Healthcare providers must learn about the importance of pain assessment and treatment during their education, and ongoing educational programs regarding pain should be a part of the continuing education process.

The importance of this issue has been recognized by the Veterans Health Administration (VHA) and we are now on the forefront of developing systematic solutions to this problem. As early as 1996, a VHA Multidisciplinary Pain Committee was appointed to develop a national pain management strategy to ensure that appropriate acute and chronic pain care would be provided to veterans. Preliminary work included an assessment of the current status of pain management in VHA and a review of the available literature including surveys, studies, reports and literature reviews/book chapters. No generally applicable studies have been performed to determine types or incidence of pain in veterans. However, a conservative assumption can be made that veterans have at least the same amount of pain as the general U.S. population. A greater incidence of pain in veterans may be expected due to the higher prevalence of trauma and psychological problems, both known to increase the incidence of pain and confound therapies. Applying the pain incidence in the U.S. population to current VHA patients, it is projected that there are 0.9 million acute pain episodes annually and 0.75 million patients with chronic pain. For the entire veteran population, we estimate 6 million acute pain episodes and 5.6 million patients with chronic pain. This represents the largest

group of current and potential patients experiencing pain within any single health care organization.

As a result of the preliminary work of the National Pain Management Strategy Committee, a recommendation was made to appoint a permanent VHA Pain Advisory Committee to advance a pain management strategy. Former Under Secretary for Health, Dr. Kenneth W. Kizer, approved a comprehensive action plan, and the importance of treating pain within the VHA was thus recognized in a formal way. Since that time, a tremendous effort has been put forth to address the issue of pain in a systematic way throughout the VHA that in many respects is in advance of efforts being made at private institutions in response to changing JCAHO guidelines.

The first major initiative was to address Pain as the 5<sup>th</sup> Vital Sign™. This was formally announced and implemented in VHA in February 1999. It was the first step in recognizing that unless pain is assessed on a routine basis, it is not validated and is not treated in an adequate way. This initiative has mandated that pain be assessed at the same time that routine vital signs such as heart rate, blood pressure, pulse and temperature are taken and recorded in the patient record. The routine assessment of pain, along with ongoing development of guidelines regarding a response to the pain score recorded at the time of assessment, will help drive improved treatment.

A subcommittee of the National Pain Management Strategy Committee has been charged with developing evidence-based guidelines to standardize and improve treatment of acute pain, cancer pain and chronic pain. Concurrently, we have also begun to collaborate with the Institute for Healthcare Improvement (IHI) to improve the delivery of pain and end of life care throughout the VHA. This collaborative effort will enable

VA facilities to strengthen their use of Pain as the 5<sup>th</sup> Vital Sign™, and utilize VHA resources to ensure that pain is assessed, treated, and monitored to achieve maximum patient comfort and enhance patient recovery.

The importance of education in making a change of this magnitude was immediately recognized by VHA. A toolkit has been developed as a means of helping the Veterans Integrated Service Networks (VISNs) implement Pain as a 5<sup>th</sup> Vital Sign™, establish procedures for pain assessment in all sites of care, provide education for healthcare providers on pain assessment, and provide for the education of patients and families. Further, in November 1999, a VA National Leadership Conference on Pain Management and End of Life Care was held. It served to highlight the importance of these issues, provided a forum for leaders from throughout the VHA to see the types of treatment programs and research currently in place throughout the system, and served to educate attendees about state-of-the-art pain management and end of life care. Finally, VHA recently funded 10 new pain residency positions to advance training in pain management and improve delivery of pain management services within our healthcare system.

I would like to make this more personal and share with you some of my own experiences at the VA Medical Center in Iowa City, Iowa. Since arriving in Iowa City in January 1998, to assume the position of Director of the Pain Medicine Division at the University of Iowa, I have had the opportunity to make a number of changes and to expand the available services. When I arrived, the pain clinic, which had been operating at the VA Medical Center in Iowa City, had been closed and some patients were being cared for at the University Pain Medicine Clinic. I have had strong support from the



Chief of Staff and the Chief of Anesthesia at the VA Medical Center in Iowa City. As a result, I have been able to reopen the outpatient pain clinic and organize an inpatient acute pain service providing epidural analgesia for postoperative pain control with specialty call coverage 24 hours/day, 7 days per week. There remains a significant demand for pain services and I hope that future expansion of services will allow us to meet a greater proportion of that demand. I would like to share with you a recent example of the type of patient encounter by our pain medicine team.

A 74 year old man recently presented to the pain medicine clinic with a chief complaint of severe left chest wall pain due to a tumor that was eroding through his ribs. At the time of his presentation he was taking only 10 mg of Oxycontin every 12 hours and had no medications available for breakthrough pain. He expressed concern about the use of narcotic pain medications and what they might do to him. His wife and daughter, who were with him, shared his concern. He made it clear that he had no misconceptions about what the future held for him, but that he did not want to suffer with pain for the remainder of his life. I explained to both the patient and his family the available options including oral pain medications, nerve blocks and delivery of pain medication within the spinal fluid. I also emphasized the fact that the narcotic pain medications were a tool that was appropriate to use in his current situation and that he should not fear addiction or a stain on his character for their use. After some relatively minor dose adjustments, he returned for a follow-up visit and reported that he had excellent pain control without any significant side effects. This could have been done earlier and he could have experienced less pain overall. However, it would have required better knowledge on the part of the referring physician and an understanding of

the issue of pain and its treatment in cancer by the patient. This is only one story, but it is repeated over and over again.

In conclusion, I would like to thank you for the opportunity to highlight an area of medical care that I believe to be vital but often ignored. I would also like to emphasize the importance of your continued interest and support for:

- 1) education for the public at large regarding issues of pain management,
- 2) increasing education regarding pain during healthcare training and continuing medical education,
- 3) research to improve treatments and document their outcome.

Improvements in these areas will have a significant impact on the delivery of healthcare and outcome throughout the United States.

Mr. Chairman, this concludes my opening remarks and I would be pleased to answer any questions you or the members of the Committee might have.

The CHAIRMAN. Thank you very much, and let me say something before I forget it, in regard to questions we might have; and that is that you have seen five members come and go. They have obligations other places. They may have some questions of this panel that they would submit in writing. My staff would help you do that. We would like to have those back in about 2 weeks, if we could; and even some members, that maybe would not be here, might ask questions, as well.

[The information referred to follows.]

The CHAIRMAN. Would you proceed, Dr. Emanuel.

**STATEMENT OF LINDA EMANUEL, M.D., Ph.D., PRINCIPAL, EDUCATION FOR PHYSICIANS ON END-OF-LIFE CARE PROJECT; PROFESSOR OF MEDICINE, NORTHWESTERN UNIVERSITY, CHICAGO, IL**

Dr. EMANUEL. Mr. Chairman, my name is Dr. Linda Emanuel. I am a General Internist with a special focus on end-of-life care and I thank you for the opportunity to provide some perspectives to your committee, along with my colleagues. I also would like to thank you and your committee for seeking out and listening to personal stories and adding your own personal experiences.

It is all too often that we tend to speak of those people who die when, in fact, it is we all who will die, and until we fully embrace what you have initiated, we will not be able to solve the problems that face us. This presentation will focus on three themes. First, I will focus on changes needed in health care delivery systems. Second, I will describe our program to educate physicians in end-of-life care, that is one step, in addition, that hopes to fill this gap, along with others of its kind. Finally I will offer some thoughts about how this committee and our society may be able to focus attention to move forward. I will not focus today on the need to bring about abroad cultural change in society-in-general, with a broad culture that needs to embrace the reality of death and the possibility of quality care.

I would like to pose the point that the health care system needs to integrate the relief of suffering into all the care that we provide. The relief of suffering is an integral goal in any illness care. Relief of physical suffering allows people to preserve social, psychological and spiritual well-being. The integrated programs must also directly support all four of these domains. This notion of whole person care is consistent with the definition of health adopted by the World Health Organization and launched by Dame Cecily Saunders, who started the hospice movement.

In these integrated programs, we must treat as a unit not only the patient, but the patient's family. This philosophy takes into account our increasingly strong data that shows us that there is widespread suffering amongst the family members, and that this, in turn, seems to foster illnesses in the family caregivers as well as exacerbate patient suffering.

Your witnesses today provide convincing cases that support this view. Please note that this philosophy supports hospice, but goes beyond hospice. Hospice is a fabulous creation that must be preserved. It is in some jeopardy at the present time; but, in addition, we need to go further than hospice. As hospice takes its message

mainstream, we need to move upstream in providing the relief of suffering to people who perhaps have a terminal diagnosis, but are not yet hospice-eligible.

In the materials available to you, there is a figure which demonstrates a philosophy in which cure and care are provided in a smooth continuum, so that Ms. Gulotta's husband and Ms. Twiford's mother should not have had to choose between a curative approach and a caring approach. In this approach, the patient should be able to function longer, be fulfilled longer, and the caregiver's function within society and within the family should be able to continue without interruption.

This approach provides a triple win. Patients stay out of expensive care settings of hospitals longer, that they do not want. Patients and family stay socially productive as long as possible, and the experience of dying can be comfortable and leave a lasting positive legacy. I would like to offer a short story here of the person who provides a right-hand function for our program in educating physicians.

Kit Meshenberg has provided public testimony around the fact that she has a disseminated and aggressive form of breast cancer. I would like to confirm that she has been, in her professional capacity, along with her illness, because of the supportive care that she has been provided, one of the most productive members of our team as we implement this national program.

To this national program now; it is a program supported by the Robert Wood Johnson Foundation that has several key premises. First, we wanted to provide the program to physicians all over the country. Second, we decided that it is not possible to wait for medical school education to provide improvements. Third, we tailored its implementation for the forums in which physicians learn best. We provided a train-the-trainer program that is both grassroots and provides leadership in medicine. It takes both to achieve success.

In the appendicial materials that are provided to you, we have listed a series of items that are provided in the curriculum materials, and the CD ROMs containing all of these and have been made available to the committee. The implementation of this program to date has reached almost half of practicing physicians around the country and has directly trained something slightly more than 10 percent of physicians.

A remarkable feature of this program is that people who have taken part in it come back for more. They come back for faculty-development programs. They come back for assistance in implementing their own versions of the programs. There is a professional renewal and revitalization going on that helps with patient satisfaction and with work satisfaction. Oddly and miraculously, an unexpected solution to a broad malaise in the health care professional workforce appears to be going on.

Finally, I would like to draw out the theme that the relief of suffering is indeed an integral part of medical care. We omitted it at our own peril and at the peril of society. The end result has been anger amongst patients and citizens and revolutions in health-care delivery and accountability demands that are more aggressive and targeted than ever before. The task of this daunting new century is to rebuild true and trustworthy care into medical care. All policy

and legislation should support the relief of suffering as an integral part of medical care.

If we do this, we have a promising model for U.S. medical care more generally. We can rebuild the whole approach to the patient and family that integrates science with care. We can rebuild the interdisciplinary team, rebuild the services that deliver care that involves the family with its care and resources without destroying it, and providing continuity from the intensive care unit all the way to the home.

I will close with two oddly tangential, but very relevant stories. First is the story of a young child who was swimming, and, as I watched this child swimming out of her depth, she gradually sank beneath the level of the water, and as it engulfed her mouth and nose, she was no longer able to make a sound, and I realized, with a profound sense of horror, that in this case, as in so many others, dying is silent.

Second, the story of a woman who presented to me in my clinic who had had a successful remission in her breast cancer, and her first request to me was for physician-assisted suicide. She asked me to treat her as her veterinarian when the time came. I did not respond to that directly, but instead sat down with her and discussed advanced care planning and created a care plan for her. A year later, still doing well, I asked if she would be willing to share her story with medical students who wanted to learn about physician-assisted suicide, and she said, "What? I never asked for physician-assisted suicide." What she wanted was quality care. So, to the point of these stories now, I hope that the committee does not wait for the demand. The poorly cared-for dying are silent. They cannot pick up the phone and call you, call their Senators or call HCFA. Please also watch the physician-assisted suicide debate. If we can do care well, this debate should melt away. Please also watch the satisfaction of the family caregivers because good end-of-life care makes for contented citizens, tapping their care without over burdening them, providing personal support to them and ensuring the economic reasonableness that this entails.

Thank you.

[The prepared statement of Dr. Emanuel follows.]

Testimony of Dr. Linda Emanuel

Before the

Special Committee on Aging

July 17, 2000

My name is Dr. Linda Emanuel; I am a general internist with a special focus on end-of-life care. Thank you for the opportunity to provide perspectives that may help you complete your duties as State Senators.

#### **INTRODUCTION TO END-OF-LIFE CARE IN CONTEXT**

As you listen, please think of this: often we talk about 'they', the dying population, or about 'patients' rather than people. But it is not only they or patients who die. It is we. We all will. So think of the people you have loved or known who have faced serious illnesses, some of whom may already have died, and think of their stories. Think of the care that you would like to have or have had for each of these people. And think too about what you would like as you too face illness and dying. After all, if we get the policy and medical care right, we have one last all-important opportunity to be a part of civilized humanity and write our script the way we think it should be.

This presentation focuses on three themes: 1. The steps needed to close the gaps in end-of-life care today – the contrast between what happens and what people want; 2. The nature of our program to Educate Physicians and End-of-life Care (EPEC); 3. Some thoughts about how this Committee might be able to focus helpful attention in the Senate to promote effective Congressional action.

#### **I. NEEDED STEPS TO CLOSE THE GAPS IN END-OF-LIFE CARE**

You have heard from prior testimony the striking gaps that exist between the manner of dying that most of us would seek and the manner of dying that we provide and impose of people in the US. We have made some progress in the last decade, but we are working on the effects of an entire era that denied death and found suffering invisible or at best annoying, and we have a long way to go.

**i. Society needs more.** Society needs to feel free of the taboo that prevents healthy discussions on dying and what that implies. Society to know what people can expect from quality care at the end-of-life. People need to know that dying well is not an oxymoron and they need to have opportunities to develop their ideas about what it is they or their loved ones will seek as they write their last legacy and take their final bow. People can then become active in finding supportive programs, in keeping their ill loved-ones productive as long as possible, in keeping their family psychologically robust even as they face bereavement.

For the aging population there are some places that will provide the most promising outreach. These are *houses of worship and community settings*. Two reasons for this have strong merit. One is that the aging populations often gravitate to their religious community. The other is that the least served and much deserving population in end-of-life is, sadly, that of people-of-color. Leaders of the communities that fit this category often note that churches are the places to find and to gain the trusting ear of people needing this kind of care.

**ii. The health delivery systems need to provide services** that include the relief of suffering as an integral goal in any illness care. Relief of physical suffering means that social, psychological and spiritual well-being can be pursued. A complete, integrated

program for palliative care will also support this pursuit in the realms of mental and social and spiritual well-being. This wholesome well-being means continued social productivity for both the patient for as long as possible (which is much longer than currently permitted by our narrow medical focus on illness and possibly on physical symptoms, and our inadequate attention to function and overall well-being) and for the caregiver.

This philosophy is distinct from a simple pro-hospice philosophy. Hospice is fabulous and must be preserved. It has brought us to the point where we can taste and experience in all ways what truly professional care is like at the end-of-life. It has preserved the true interdisciplinary team. It has preserved the respect for the psychological and spiritual and social care of the patient. *But more is needed than comfort for the last moments of life. Palliative care should be available 'upstream.'* People should not have to choose between hospice and cure. People should not have to choose between fighting to live and letting entirely go. Palliative care, and hospice care when done as it seeks to be done, involves providing relief of suffering as an integral part of illness care whether cure is the primary goal or the secondary goal.

See Fig 1.

In this approach, comfort and maximal function are preserved as long as possible and as a smooth continuum of shifting goals as death and loss of function become finally inevitable. In this approach, there is a *triple win: patients stay out of the expensive care setting of hospitals longer; patients and families stay socially and economically productive as long as possible; and the experience of dying can leave a lasting positive legacy.*

**iii. Professionals from all fields need core competencies in end-of-life care.** If these goals are to be accomplished, the professionals providing hands on care need core skills. While it is important to have specialty training programs to keep the discipline rigorous and to keep it progressing along with all the unprecedentedly powerful technical possibilities in palliative care, the key issue now is that few of our practicing professionals have been trained in the core skills. Core skills need to be defined and disseminated to physicians, nurses, social workers, pastors, pharmacists, and administrators. Within the nursing and physicians professions, these skills need to be defined and disseminated among all generalists and all specialists. There is no group of nurses and physicians who should be ignorant of the needs of palliative care toward the end of life. Dermatologists care for those with skin cancer. Radiologists perform comfort-motivated x-ray or laparoscopically guided procedures to relieve fluid build up. Surgeons care for the dying routinely. Many die in intensive care. Nurses have specialized skills for each of these and other categories of service.

## **II. THE PROGRAM TO EDUCATE PHYSICIANS IN END-OF-LIFE CARE**

The program to Educate Physicians in End-of-life Care (EPEC) is a Robert Wood Johnson Foundation funded initiative that takes as a key premise that *physicians all over the country* need the core skills of end of life care now. It is not possible to solve the problem with physicians alone but it is not possible to solve the problem without



physicians. As physicians, we started this program to take proactive steps toward that portion of the solution that we bear responsibility for. Another key premise is that it is *not possible to wait* for medical school education to improve matters and send better trained doctors into the field. A third premise is that physicians learn best with forms of adult learning that involve *collegial transmission* of skills. A fourth premise is that the substance of the education should be *high quality* clinical material that is readily applied to practical issues in patient care.

With these premises in mind we designed a *train-the-trainer program*, using a national and international panel of experts in the end-of-life field and in physician education to write modular materials that could be taught in a variety of settings and that could also train the learning physicians to become teachers of the material. This grass-root professional model was complemented by a top-down approach that included involvement of the leadership in medicine, whether from the American Medical Association, our founding partner, from specialty associations, from college Deans or from highly respected individual physicians.

Now in its fourth year, EPEC has produced *core curricular materials* that have defined the core competencies for end-of-life care and that are available as clinical learning material, as teaching manuals complete with handouts, as slides in electronic or acetate versions, and accompanied by clinical teaching trigger video tapes. All this is also available as a CD-ROM (50 have been made available to you) combining all of the above and can be found and fully downloaded from the web. The RWJ Foundation holds the copyright for all the EPEC materials, and license to use and modify the materials for educational purposes with acknowledgement of the source is automatically granted in writing on the bottom of each page of the curricular materials.

To date, the program's *implementation and dissemination* has come close to our outrageously ambitious dreams. Our team has directly trained about 600 physicians. Physicians were selected to cover all the states, and to meet our criteria for showing evidence of respect among colleagues, having institutional backing to implement EPEC training and having a realistic plan for its effective implementation. Each of these physicians has qualified as an EPEC trainer and a vast majority have gone on to teach EPEC materials in their own setting. We have had trouble tracking the full impact of EPEC, largely because the impact appears to be much larger than our tracking system was set up to allow for. We can calculate a conservative estimate that if an average of 100 physicians has been trained by each of our trainers, then some 60,000 physicians in the US are now EPEC trained, or approximately 10 of physicians. Possibly a more accurate estimate would more than double that, for more than one fifth of physicians in the US having received EPEC training. In addition to this direct and second-tier colleague-to-colleague training, last year we mailed the CD-ROM to all the Deans of US medical schools and to approximately 300,000 physicians, *reaching half the practicing physicians and all the medical schools in the US* in this fashion. We surmise that many others will have been gleaned indirect learning through some of the less formal and formal activities that will have been influenced by EPEC. Ultimately, we hope to have reached all physicians in the US in one fashion or another.

Currently our program is in a developmental stage that we refer to as *Partnership Development*. We are continuing our own trainings, we are supporting our trainers who are implementing the program, we are providing faculty development for a select group of master teachers, and we are developing partnerships with managed care groups, with business groups on health care, with specialty societies, with medical schools and others who are interested in making EPEC into something of their own for their own professionals or constituencies.

### **III. HOW THIS COMMITTEE MAY PROVIDE HELPFUL THEMES TO FOCUS ON**

In these final words, allow me to point to a few key thoughts for the Committee that can helpfully focus attention.

#### **i. The relief of suffering is an integral part of medical care**

This always has been so in the history of the profession but tragically got lost in the scientific enthusiasm of our 20th Century. We omit it at our own peril and at the peril of society. The end result has been anger among patients and citizens, revolutions in healthcare delivery systems and accountability demands that are more aggressive than targeted. And still we have not really understood the point. The task of this dawning new century is to rebuild true, trustworthy care into medical care. All policy and legislation should support the relief of suffering as an integral part of medical services.

**ii. Relief of suffering should occur across the spectrum of illness and all venues**  
Hospice and palliative care for the actively, imminently dying is good, but not enough. The people and their families who suffer from the effects of severe arthritis or progressive dementia should not have to wait until their prognosis renders them hospice eligible to get relief of suffering. The relief of suffering should be taught to physicians and other professionals in all disciplines from pediatrics to primary care medicine to surgery, cardiology and oncology. It should be taught to all medical professionals from nurses to social workers, pastors, pharmacists and physical therapists. It should be available in Intensive care units, ambulatory clinics, long-term care facilities, and in the home. The relief of suffering should be an expected part of service delivery design and quality control among medical administrators and medical industry or policy designers in all service settings.

#### **iii. Quality care preserves economic productivity of patients and caregivers**

The suffering of a patient with serious illness affects not only the patient but also those who are connected to that person – his or her loved ones, his or her dependants, his or her work colleagues, and his or her community. You have heard the data that shows how many quit or lose a job, take a second or new job, forgo an educational program, become depressed, or otherwise materially suffer because of these unsupported caregiver burdens. We have all heard of people with serious illness remaining fulfilled and productive in the workplace. I have described our experience with the EPEC Operations Director who has worked as or more productively than other team members throughout her chemotherapy for a supposedly aggressive disseminated breast cancer. To support those who suffer allows those who are economically and socially productive to continue

to be so. It allows the social fabric to remain knit even when a person is dying, and reknits it after a person dies. It is both basically civilized and economically sensible.

#### **iv. End-of-life Care Provides a Promising Model for US Medical Care**

If we can solve these problems, we can solve the problems in medical service delivery in the US today. As we all sink into illness and face our own mortality, we can imagine that if things go as we would wish - so that we can say goodbye, leave our house in order, leave our loved ones with a way to go forward, leave a story about ourselves that we have written with those we choose to write with until the very last chapter - then we will have achieved something in the delivery of medical care that goes beyond just end-of-life care. Right now, the problems in medical care pose you with political problems - seemingly greedy professionals who respond to accountability by being demoralized and resentful, angry citizens driving managed care backlashes, legislative responsive rather than proactive solutions. When you are dying our current problems could likely pose you challenges of depersonalization, spiritual truncation, social abandonment, physical and mental pain. But if we can implement quality end-of-life care, this can provide a model for the proactive rebuilding and revitalization of medical care in the US and beyond as it should be. We can rebuild the whole approach to the patient and family that integrates science with care; we can rebuild the interdisciplinary team; we can rebuild service delivery that involves the family without destroying it and that provides continuity from the intensive care unit to the home; we can remodel and revitalize our existing administrative and institutional structures accordingly; we can reimbursement right so that it works for patient care and for the national economy.

#### **v. Quality End-of-life Care makes Financial Sense.**

Finally, the bottom line. If we do it right, quality end-of-life care, including upstream relief of suffering for the long term seriously ill, it will cost less than or not more than the current system. And as noted above it will yield social and economic productivity that will further offset health care costs.

Thank you for your time and attention. We in this field look forward to being of assistance to you in any way we can as you move forward with your leadership to improve end-of-life care for all of us.

The CHAIRMAN. Thank you, Dr. Emanuel.

We have been joined by our colleague from Arkansas, and I would defer to you now if you want to say something, as well as ask questions.

#### STATEMENT OF SENATOR BLANCHE L. LINCOLN

Senator LINCOLN. Thank you, Mr. Chairman, and first of all, I would like to apologize for being late. I am one of those sandwich individuals who is sandwiched in between small children and aging parents, and I certainly am very, very pleased and appreciative to our Chairman for his leadership in this issue, and pleased that the Special Committee on Aging is addressing end-of-life care.

It is not an easy topic to discuss, and thank you to our panel of witnesses that have been willing to come here to discuss this very incredible issue. That is really why we are trying today, to begin the discussion. As a young woman who grew up within walking distance of both sets of grandparents, being able to assist in their years when they were dying—a grandmother with Parkinson's disease that lived across the street, another grandmother with cancer who lived in our own home for the last 2 years of her life—there is a lot more to this discussion than just medical, technical things that we need to talk about in terms of end-of-life care.

There is also a sense of the generation that is responsible, the guilty feeling that you feel when you are not at home and you have moved away, when caregivers are no longer across the street or down the road. The fact that our society has changed immensely from those of us who grew up in a very loving and comforting and supportive situation; and that is something that we do need to deal with and we need to focus in on it and recognize what can we do to provide that same quality of care in our twilight years to our parents, to our grandparents and, certainly, to lead away so that it will be there for us, as well.

It is hard, when you grow up knowing one way of life and then recognize that you, yourself, will probably not be the beneficiary of that, as you have moved around to many different places or far away from your home. As one of the baby boomers on the committee, I am tremendously interested in the positive, healthy aspects of aging, as I am the treatment of health disorders for older Americans, which we have addressed very well under the leadership of this Chairman and this committee.

Now that most Americans can expect to live longer lives, thanks to the advances of science and medicine, we really, truly need to focus more of our attention on the end-of-life issues. My husband's grandmother is 103 next month, a miraculous woman who is doing amazingly well, and yet I look at my own parents, a generation younger, who still are having many difficulties in the aging process.

I have worked tremendously with our hospice care in Arkansas, and it is interesting to note the different challenges that we meet in hospice care and end-of-life care in large, rural States. The fact that getting to the elderly in rural areas, if, in fact, they do not have relatives still alive and close by, is very difficult and, certainly, recognizing those challenges and doing something with them, I think, is really important.

The leading causes of death in this country are congestive heart failure and cancer, chronic illnesses that are accompanied by physical pain and disability. We need to be sure that patients do understand the ramifications of their medical condition and that they have access to the appropriate relief, certainly pain relief, but certainly counseling, as well, as Dr. Emanuel has alluded to in her discussions with patients.

Family members need to know what medical options are available to their loved ones and should feel comfortable discussing such matters with doctors and with their loved ones, something my sisters and I have found tremendously difficult, much more so than we have ever imagined. With a husband as a physician, in preparation for this hearing, Mr. Chairman, I asked him last night what kind of training he had received in medical school for end-of-life care, and there was this blank look on his face. He is an OB-GYN, so his is the opposite end of the spectrum, in bringing life into this world.

But nonetheless, as a physician with 4 years of medical school, 4 years of residency and 2 years of a fellowship, I think it was basically his oncology rotation that taught him the most about end-of-life care, and I do think that medical schools can possibly offer us a great deal more in training, in pain relief management and how to counsel patients with chronic illness, and I think Dr. Emanuel has alluded to some of that.

Certainly, I think the most important thing is not to wait. Without a doubt, with the increasing number of elderly in this country and what we are going to run into in the next 25 years in the aging population, if we wait until it is a crisis situation, we will not be prepared. This is not something that we are going to find a pill to solve. It is going to take an awful lot of our own intuition, our own involvement and certainly our own emotion, the willingness to make difficult decisions.

So, I am delighted that we are listening here. I do apologize for being late, but I have read some of your testimonies. Certainly, this is a priority issue for me as a Member of Congress and certainly as a citizen. I think it is something we have to devote our attention to. So, I am eager to continue the discussion and I appreciate the Chairman's indulgence.

Thank you.

The CHAIRMAN. We will have a hearing in September on end-of-life and how Medicare interacts with it, yes.

Senator LINCOLN. Great.

The CHAIRMAN. Did you have some questions you wanted to ask?

Senator LINCOLN. Not in particular. As I said, I have read some of your testimony and just—

The CHAIRMAN. Well, that is OK.

Senator LINCOLN [continuing]. The tail end from Dr. Emanuel was good.

The CHAIRMAN. By the way, in our efforts to help educate the public at-large about this discussion that we do not often have a discussion about, and that is why Americans may not feel comfortable about it, I thank C-SPAN for taping it for later broadcast.

As I ask questions, I might direct them to a specific person, but I would also encourage, since all of you have had some experience

in this area, if there is something you want to add or something you want to contradict what the other has said, feel free just to break in at the end of the first comment. I am also going to ask you to think through the period of time that I am questioning you about, and you may not have anything to say about it; but if you do, I would like to have you comment on it at the end of our questioning; and that is whether any of you in your study of end-of-life care as it is practiced in America or the lack of practice of it, whether or not you have any knowledge of anything that we could learn from other societies, other nationalities or other religions, that we maybe ought to look at in regard to the fact are we missing something in America that other societies practice.

I am going to start with you, Dr. Rosenquist, for my first question. I would like to, obviously, applaud the Veterans Administration for its efforts to have pain assessed every time that a patient is seen by a doctor, just like you would other vital signs. I do not know how accurate or common a belief this is, but let me ask you this: most of us think that even with all the advances that medicine is making, there is a lot of pain that is simply not treatable. Now, is that an accurate belief or can almost all pain be successfully treated?

Dr. ROSENQUIST. The vast majority of pain can be treated successfully, certainly not 100 percent, and I would be amiss if I said that we could successfully treat all pain; but there are many different types of pain, some of which are physical, some of which are what we call nociceptive, meaning I bang my shin on the end of a table and I hurt from that, or acute surgical pain that we are very successful in treating. Sometimes we have pain from a tumor invading a nerve plexus, or into things that we cannot control as well with common pain medicines, but we can help control some of them.

Sometimes the pain is unresolved issues with our family, our friends or our life. You have to sit down with people long enough to get to know them and allow them the opportunity to share some of their concerns about what is really causing pain. If you fail to look at all those things, including the spiritual, you will never be successful in treating a large majority of the pain that is out there.

The CHAIRMAN. Does anybody want to add?

Dr. Lynn.

Dr. LYNN. Just a small addendum; in the current arguments surrounding end-of-life care, it is important that we recognize that there is no one who has to be in terrible physical pain at all. There is no one at all, because we could always induce anesthesia or sedation, so the person would not have that pain. So, in a sense, Dr. Rosenquist's answer is within the frame of keeping the person functioning and awake. Sometimes, at the very end of life, that is not part of the constraint and it is all right for the person to be quite sedated; and then if the person has terrible symptoms of almost any sort, it is important that we know that no one has to endure terrible physical symptoms.

The CHAIRMAN. Ms. Todd, I commend you for your service and particularly what you are trying to do in education and outreach, but I would also compliment hospices generally in America. I have had a chance, just in my capacity as a Senator—thank God, not yet

as a family member—to visit people and visit hospices and read a lot of their literature and be somewhat supportive of them. I have been satisfied with what I have seen. Now, obviously, in our September hearing, we are going to be focusing on hospice and how to make it stronger when we hold that hearing. I know it may be too early to ask about this, but what results have you seen so far from your own educational outreach efforts that you described in our Sioux City, IA area?

Ms. TODD. It has probably been within the last 6 months that we started with our end-of-life task force, and an advanced care planning project. We are promoting the "Five-Wishes" document, which is a living will and durable power of attorney, but it is written in lay terms so people can understand and address not only medical wishes but also personal, emotional and spiritual issues of seriously ill persons.

Even though five wishes is recognized as a legal document in Iowa, we have been advised by an attorney to have people continue to complete the Iowa Bar Association legal document. We then copy and shrink the legal document to a billfold-sized card. The cards are laminated to enable people to carry the cards with them when they go into the emergency room or to the hospital.

Recently, I have been asked to speak at five different groups regarding the Advance Directives. We took the Five Wishes document to senior citizens to obtain feedback about Five Wishes and at when we were trying to make a decision about whether we would use Five Wishes. People responded "This is a wonderful document. It asks the questions that I think are important." One of the ladies said, "I have a living will and a durable power of attorney, and I have tried to talk to my daughter about my wishes. Every time I tried to talk with her, she would cry and did not want to hear it. So this will give me the tool that I can go back and talk with her."

The Moyers series will air this fall, and we have planned a community outreach that will span the Siouxland community. This has been just an incredible experience, as you start to see churches, community groups, nursing facilities, hospital staff and health care professionals planning for outreach on end of life care. Whenever the conversation opens the discussion of end of life care somebody always has a story to tell. So, providing those opportunities are ways for people to start learning about end-of-life and that is very, very important.

We have initiated the EPEC program that Dr. Emanuel talked about. The medical director that currently works with Hospice of Siouxland is a trainer. We have two other physicians that have participated in EPEC as well. They are now starting with the family practice residency program in Sioux City; once a month, an EPEC module is presented for the family practice residents. So, we hope, a step at a time, that we are making a difference with our educational efforts.

The CHAIRMAN. Doctor, did you want to add? That is fine, because that is what I want you to do, if there is something you can add to what Ms. Todd said.

Dr. EMANUEL. May I just add one point and confirm for the record, if I am accurate, which I hope is the case, that as we train professionals of all kinds, nurses, physicians, social workers and

others, in end-of-life care and try and move the experience upstream, that when professionals consider the possibility of hospice eligibility, that they do not have to believe that the patient is going to die in 6 months or less, but rather that, on average, people with that diagnosis tend to live about 6 months. So, they could live longer.

At the moment, we tend to refer people to hospice way too late, so that, just as your witnesses described, hospice experience may be confined to days at the end-of-life when, in fact, it was intended to last for months and months. So this is a point of information that needs to get out to the public generally, as well as to the professionals.

The CHAIRMAN. Dr. Tulsky.

Dr. TULSKY. This was a point that came up earlier with the previous set of witnesses, and I want to add on to what Dr. Emanuel said. It is very difficult for physicians to prognosticate, and there is always going to be uncertainty; and there are a lot of reasons for the difficulty that we have when we need to tell someone how long they are going to live.

Some of those are emotional on the part of the physician, not wanting to be the bearer of bad news, but some of it has to do with the level of uncertainty; and there is just one statistic I want to share with you. That is, to be absolutely certain that a patient is going to die in 6 months. The median survival of that patient needs to be 2 weeks. This is the only way to make sure that at the tail-end of the patients, you have no patients that live longer than 6 months. If you are worried about a patient outliving their hospice benefit, you are going to be forced to refer these patients very, very late.

The CHAIRMAN. Thank you. Obviously, that is something Senator Collins was talking about and something for us to consider in our hearing in September. Now, Dr. Lynn, obviously you express a great deal of passion for wanting to do more to improve the treatment of dying patients, and it seems that if a provider or practitioner is willing to make the commitment, that they can make it happen, that we reduce waits for pain medication; but as we all know, doctors and nurses are busy and stressed.

Under those circumstances, what is the key to getting them to make this a real priority?

Dr. LYNN. Let me broaden your question, not just to pain, but broaden it to getting good end-of-life care, a real priority.

The CHAIRMAN. You can do that.

Dr. LYNN. Quite simply, we have to learn as a culture to value it. We have been able to find good end-of-life care for heart-and-lung-failure patients only in managed care, the VA and a few hospice programs, because everywhere else, they will go under. They will not be able to support themselves financially. We have no measures in HEDIS, no measures in HCFA, no measures in Medicare that value end-of-life care. We do not make it a priority for the CDC. We do not make it priority for HRSA. We do not make it a priority for HCFA.

One out of eight Medicare dollars is spent on the last month of life, and yet the quality measures there are completely gone. We do not measure it at all. It is just pervasive. We built a care system



around the thought that we had heart attacks in 1965, and we built one heck of a care system for that. Anywhere in the country, if I fall over with a heart attack, I can get resuscitated within 3 minutes. I have got a pretty good shot of that. Almost anywhere in the country, if I needed Meals-on-Wheels on Saturday, I cannot get it. If what I need is continuity of care by a doctor, it is not paid for.

I mean, we do not know how to value that. How do we get from here to there? That actually builds on a question you were saying earlier—what can we learn from other countries; what can we learn from elsewhere? We need a period of innovation. We need a period in which it's safe to try out new things. At most, we have one Medicare demonstration right now dealing with this population. One. I mean, we are talking about doubling the number and eventually tripling the number of people going through this. We are talking about not knowing how to implement the things we already know.

We need something like the Ryan White Act for end-of-life care, where we send some agency out to figure out how to get what we already know in the hands of people who need it, and we need to do it efficiently right from the start. It cannot be a gold spoon, you know; it cannot be just sort of run up the bills, because we have got a huge number of us all coming at the system at once. So we have to learn how to do this well and reliably and efficiently, so that every American can say—if you listen to the stories today, there was a very interesting term, both in the stories the Senators told and the stories the witnesses told.

The people who told a good story did not say, "Boy, wasn't that a good care system to rely on?" They said, "Weren't we lucky somebody turned us to hospice? Weren't we lucky we ran into that aide?" We do not say that about anything else in health care. We expect the appendix to come out right and we expect the surgery to be done right. You know, people have learned to count on getting the right treatment. Not in end-of-life care. Everybody feels like they are on a roulette wheel, like they just put their pop on a roulette wheel and spun it, and it might come up bad.

We have to learn to develop care systems that are reliable. What are other countries doing—tremendous innovation, putting things together in very different ways, mixing housing in with end-of-life care. I am working with a group in Sweden that actually figures out how they could take care of a particular patient in a reliable way anywhere in their city, and try out new things and evaluate them.

We have got a golden period of about a decade before we start getting huge numbers of people needing us all at the same time. If we could really buckle down and figure out how to do it right, by the time we got to that point, people could say, "I would rather live forever. I would rather live like I was at 21, but given that I have to grow old and I have got to get this array of illnesses, boy am I glad that I have got a care system I can count on." And we have this little piece of time to do that, but we will not do it by a new drug. We will not do it by the genetic code. We will do it by figuring out how to take the things we already kind of know, out of hospice, out of PACE, out of the kind of research that James

has been doing and the kind of education programs that Linda talked about, putting them together in a care system that really works; and if we miss that chance, we are going to learn to do awful things. We are going to learn how to walk out on one another. We are going to learn how to, in fact, deliver on suicide, because we are not going to face the kind of suffering that would happen if we took today's care system and tripled the number people come at it.

So, this is the chance. This is the period of time we can do it.

Ms. TODD. Senator Grassley, if I could just make a comment, hospices across the country are continually worried that they are going to admit a person to Hospice and they are not going to die in the right amount of time. So, Hospices experience scrutiny that has come from HCFA. In our own program, we have had charts reviewed just endlessly, where we are having to send complete documents in to HCFA because the person had a non-cancer diagnosis and they might live 3 months or 6 months. Our median length of service on hospice is 22 days.

So, this scrutiny almost puts up a barrier to hospice. Especially when physicians are challenged and questioned about predicting prognosis. This activity stifles referrals to hospice.

The CHAIRMAN. Senator Lincoln.

Senator LINCOLN. Thank you, Mr. Chairman. I did think up a couple of questions; but just to what Ms. Todd mentioned, in visiting with the hospice in Arkansas, they did express a great deal of concern over that, because what happens is, when you do get them into the system too early or into the care too early, then when they need it the most, it is not provided for and they are having to pay for it out of their hospice budget without any reimbursement of all, and that puts in jeopardy the whole program in many instances. So, it is a point well-taken.

Just a couple of questions to Dr. Tulsy. I have been fascinated with the new program at Duke, the Institute on Care at the End-of-Life. We, in Arkansas, have one of two medical schools in the country that have a program in gerontology, and hopefully we can do more on that with our new center on aging that is coming around in Little Rock. But the unique combination of a medical center and a divinity school certainly offers a new and forward-thinking approach to end-of-life care.

Having an uncle that was an Episcopal minister—still is; he is retired—my father-in-law, being a doctor, they kind of worked in tandem. But it is a fascinating idea of putting those schools together. How did the institute really decide to combine the two schools in the initiative?

Dr. TULSKY. It actually came—a lot of it, to be perfectly honest, came from the outside, came from the donor, the person who gave the initial gift to establish the institute—

Senator LINCOLN. Oh. Is that right?

Dr. TULSKY [continuing]. Someone who is actually a graduate of the divinity school, Hugh Westbrook, who has also been very involved in the hospice community. So, he wanted to be able—and he is an ordained minister himself and he keeps that ordination, and so he wanted to be able to see that we would be able to integrate the spiritual with the medical. He knew, as well as everyone at

Duke knew, that if that institute were created in the medical center, even if an expressed mission of the institute was to integrate the spiritual into the medical, there would be a huge sucking noise toward the medical center and the issues of the spiritual would really be lost. To be able to keep them on the forefront, we decided to create this arrangement, where the institute is based in divinity, but in my position as associate director, I'm basically in charge of the medical center side of things and we work extremely closely—it is fully integrated in the way we work together.

Senator LINCOLN. That is fascinating, because I think the more that we work with the medical community on that—I know my husband's partner, when he was teaching at the medical school, was the moil for the Memphis community. The Jewish community had figured out it was easier to train the physicians in the spiritual side than it was to train the spiritual leaders in the medical side of things. So, when we combine those things, we certainly are very productive, I think. So, I am very interested in any more that you can enlighten us on that as we move along.

We also have in Arkansas—really one of our better aging facilities is the VA. I think our only federally certified Alzheimer's facility is our VA hospital in North Little Rock. Dr. Rosenquist, in your testimony that the VA is providing leadership in this area of pain management, are medical professionals outside the VA system using the pain as the fifth vital sense approach?

Dr. ROSENQUIST. Pain as the fifth vital sign is really something that was developed by the American Pain Society and was adopted by the VA as a means of kicking off the program and providing an impetus for this program to grow and have an identity. So, I really have to give credit where credit is due. Pain as a fifth vital sign is something that was developed by the American Pain Society.

Senator LINCOLN. So, everyone has access to that information. It is not just a VA program that was started.

Dr. ROSENQUIST. Absolutely.

Senator LINCOLN. Obviously, we have a lot of educating to do for all of us, in terms of where to go for things. Just in closing, Mr. Chairman, I would like to highlight what Dr. Lynn said. I have not been on Capitol Hill as long as many of my colleagues. I am one of the more recent additions here and did not come to politics from a background in government. But what I have noticed up here is it does take us, on average, somewhere from 6 to 8 years to pass legislation, really thorough comprehensive legislation. If all we have is a decade, which, in best estimates, that is kind of it, it just even gives more credence to the fact that we need to be here in these kind of hearings and how much, certainly, we appreciate the Chairman's leadership in focusing on issues like this, because 10 years, a decade, even a quarter-century is not a long time when you are talking about preparing for something of this magnitude.

So, we appreciate your input and hope it will be a continuing relationship that the committee has with all of you.

Thank you.

Dr. LYNN. Let's do it.

The CHAIRMAN. Thank you. I have no more questions, and I want to thank all of you for participating. Your testimony has been tremendously helpful. I particularly want to thank my two constitu-

ents, Dr. Rosenquist and Ms. Todd, for coming. One of our main themes of this hearing was the need for all of us to be knowledgeable consumers of health care when we find ourselves in the role of caregivers for a loved one.

I would like to list six things that we should expect and even demand for those approaching end-of-life:

- Honesty from health care professionals about prognosis and about what to expect along the way;
- Pain being taken very seriously as a medical issue and treated with the best palliative care medicine has to offer;
- Care that is continuous, coordinated and comprehensive;
- Respect for personal preferences about treatment methods and the setting;
- Full information about options and support services for physical, emotional and financial needs;
- And, being treated at all times with compassion and care as a person and not simply as a disease.

I thank all of our witnesses for coming and your contribution to this discussion. Thank you very much. Meeting adjourned.

[Whereupon, at 3:20 p.m., the committee was adjourned.]

## A P P E N D I X

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Senator Chuck Grassley's list of six things everyone should expect at the end of life:

- Honesty from health care professionals about prognosis and about what to expect along the way.
- Pain being taken as seriously as other medical issues, and treated with the best palliative care medicine has to offer.
- Care that is continuous, coordinated and comprehensive.
- Respect for personal preferences about treatment methods and setting.
- Full information about options and support services for physical, emotional and financial needs.
- And finally, being treated at all times with compassion and care as a person, not simply as a disease.

**SENATOR JOHN BREAUX'S  
END-OF-LIFE CARE CHECKLIST  
FOR SENIORS**

**Before visiting your doctor, think about any questions or concerns you have and want to discuss with your health care provider.**

**When visiting your doctor, bring a list of all medications you are taking.**

**Ask your doctor about hospice services in your area.**

**Let your doctor know if you don't understand an explanation regarding your diagnosis, likely symptoms or side effects of medications.**

**If you are in physical pain be sure to tell your doctor, who will likely ask how intense it is on a scale from one to 10.**

**When visiting your doctor, consider bringing a family member or friend.**

**Talk to your family and loved ones about your treatment preferences, and consider documenting your wishes in a living will.**

**Consider appointing someone you trust to make your health care decision, in case you can no longer make decisions for yourself.**

**If you are feeling overwhelmed or sad, consider talking to a pastor, chaplain, rabbi or other trusted person in your faith community.**

**Keep open lines of communication with family, friends and your health care providers. The more you tell them the more likely you will get the care you need!**

