

**EMPOWERING PATIENTS AND HONORING
INDIVIDUALS' CHOICES: LESSONS IN IMPROVING
CARE FOR INDIVIDUALS WITH ADVANCED ILLNESS**

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BEFORE THE
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WEDNESDAY, JUNE 13, 2012

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

The Committee met, pursuant to notice, at 2:03 p.m., in Room SD-562, Dirksen Senate Office Building, Hon. Herb Kohl, chairman of the committee, presiding.

Present: Senators Kohl [presiding], Whitehouse, Collins, and Manchin.

OPENING STATEMENT OF SENATOR HERB KOHL, CHAIRMAN

The CHAIRMAN. Good afternoon to everybody. I would personally like to thank Senator Sheldon Whitehouse for holding today's hearing. Senator Whitehouse is tackling a sensitive but very important issue today, and we thank him so much for that.

We're here to discuss care for individuals with advanced illnesses. With the rapidly growing number of older Americans who are living longer than ever, we're going to face a continuing rise in the number of people suffering from chronic diseases, especially in their later years. These people deserve to have their wishes carried out when it comes to their healthcare at the end of life. But, as a recent article in the "Wall Street Journal" made clear, it's important for people to understand that some living wills are better than others, and even if you have one, it's possible that your wishes may not be followed.

Many living wills are simply too vague or fail to cover unanticipated situations. If people are considering a living will, then they need to work out the details with the help of a qualified doctor and a loved one.

In my State of Wisconsin we have excellent models of clear advance directives and health systems that adhere to patients' wishes. One such model is Gunderson Lutheran Medical Center, in La Crosse. Their written testimony submitted for the record today states 96 percent of all adult residents of La Crosse County who died had some type of advanced care plan, and treatments were consistent with the patients' wishes over 99 percent of the time. Imagine that. Models such as this need to be replicated throughout our country. It's vital for patients, their families, and our overall healthcare system.

Today, our witnesses will highlight some of the best practices and discuss ways to improve our healthcare system, so that it can better serve people with advanced illnesses. As I already stated, an important part of this care is making sure that treatment decisions align with patients' preferences and goals. Nothing should get in the way of providing comfort to people suffering from advanced illnesses. Our hope is that today we will discover some additional ways to promote better patient care.

Once again, I'd like to thank Senator Whitehouse for his leadership on this issue, and at this time, I turn the hearing over to Senator Whitehouse.

STATEMENT OF SENATOR SHELDON WHITEHOUSE

Senator WHITEHOUSE [presiding]. Thank you, Chairman Kohl, for starting us off today with those very thoughtful remarks, and let me take this opportunity to thank you for your leadership of the Aging Committee and for the wonderful work you've done to protect our seniors from fraud and abuse, to make sure that Social Security is, in fact, secure, to address long-term care, and, of course, to address the question of end-of-life care, where your State had such a leadership role.

I'll do my, like, book tour moment here, and point out that there's a wonderful book called, "Having Your Own Say," that has come out of the Gunderson Health system, and a number of my colleagues will be doing a Washington conference around that book and around this issue with the coalition to transform advanced care, which is a wide group of industry and other supporters of what we need to do here.

Like many of the folks who are here, this hearing is important to me on both professional and personal levels. I've been working on adding dignity and affirming choice in end-of-life care back since I was attorney general in Rhode Island, working then with Dr. Mor's colleague, Joan Teno, who brought to our attention early on that the families of people who died in Rhode Island reported more often than not that they died in pain, and of the family members who had reported that their loved one died in pain, they reported more often than not that the level of pain was severe or excruciating. And so, that gave us an important opening into trying to make sure that people were protected from unnecessary pain.

The groups that we started working with, AARP, religious leaders, the medical society, Brown University, still gather, and I should salute them for just this week getting the, I'll get the name right, Medical Orders for Life Sustaining Treatment Law passed and signed into law by, I guess, your former colleague, we didn't overlap, now Governor Chafee. He signed that law into effect on Monday, this week, June 11th. And that's a victory for that group.

Personally, I have had the experience of loved ones dying with great dignity, and without pain, and in a manner consistent with their own wishes and desires. And although grief always casts a shadow, the shadow of that grief, I think, is lightened by the experience being one that is dignified, humane, desired in its means, and pain free.

I have also had the experience of loved ones dying with treatment being administered to them against their will, and not only

is it a tragedy from the point of view of this person, who I loved very much, but it was also a lingering burden that added to the shadow of grief, that we were unsuccessful in securing her wishes, and that the machinery of healthcare took over, trampled what she wanted. This was a very, very dignified, proud, and independent woman, and she ended up dying with a ventilator tube down her throat. And we had been asked over and over again, don't let that happen. And so, it adds to the shadow of grief when people don't get their wishes maintained.

So, it's really important, I think, that we take the time in this hearing to take a look at these issues to do what we can to make sure that the system is one that is akin to what was described in a 1997 report of the Institute of Medicine, a human care system, they called it. The quote, "People can trust to serve them well as they die, even if their needs and beliefs call for a departure from typical practices. It honors and protects those who are dying, conveys by word and action that dignity resides in people and helps people to preserve their integrity, while coping with unavoidable physical insults and losses."

Unfortunately, our system for delivering care to those with advanced and serious illness regularly fails to meet that standard. The Dartmouth Atlas of Healthcare shows that in the last 6 months of life, chronically ill Medicare beneficiaries in some regions of the country spent more than 3 times as many days in the hospital and more than 10 times as many days in an intensive care unit as patients in other regions. This regional variation overrides patient preferences about how to manage their care.

As Americans live longer, we are increasingly suffering from a greater burden of chronic diseases. More than three-quarters of Americans 65 and older have at least one chronic disease, and as the baby-boomer generation ages, the percentage of the U.S. population age 65 and older is projected to increase from 11 percent of the population now, to 16 percent by 2020, and almost 20 percent, almost 1 in 5, by 2030. So, our physicians, our nurses, our clinicians have to be properly trained to not only conduct the medical miracles that we see every day in our wonderful medical profession, but also be trained to have conversations about care options, and about care goals, and about ensuring that patients can make their wishes known, and can have their wishes honored.

So, I'm delighted that we have the witnesses here today. I'll introduce them specifically later on. But, Senator Collins is here. I know, from previous hearings, how deeply she feels about this. I'm honored that she has joined us, and I'd like to invite her to say a few words at the beginning of the hearing.

STATEMENT OF SENATOR SUSAN COLLINS

Senator COLLINS. Thank you very much. First, Senator Whitehouse, let me join you in commending our chairman for his leadership. I know there will be subsequent hearings before he retires from the Senate, but I don't want to let this opportunity pass by without thanking him for his leadership of this committee and all the work that he has done.

And I want to thank you, Senator Whitehouse, for your interest in this hearing to look at best-practice models of hospice and pallia-

tive care for patients with advanced serious illnesses and complex care needs. Advancements in medicine, public health, and technology have enabled more and more of us to live longer and healthier lives. When medical treatment can no longer promise a continuation of life, however, 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 and their needs.

Clearly, there is much more that we can do in this country to relieve suffering, respect personal choice and dignity, and provide opportunities for people to find meaning and comfort at life's end.

Fortunately, also, there are some wonderful models of coordinated patient-centered care for individuals with advanced illness. In his cover story in this week's "Time" Magazine, Joe Klein writes about his own experience during his parents' final days. His mother and father were patients in The Fairways, a Pennsylvania nursing facility in the Geisinger Healthcare system. Both parents had multiple and complex health conditions, including dementia. Prior to their admission to The Fairways, Mr. Klein said that there was no coordination among the flotilla of physicians involved in their care. All of this changed at Fairways. He was consulted about every development or adjustment of medication.

While he still characterized his parents' decline as horrific, he wrote that he no longer felt so powerless, guilty, and frustrated. He, instead, was part of a team that made their passage as comfortable as possible. And, Mr. Chairman, I would ask unanimous consent to include Mr. Klein's article in the hearing record, since it's so on point.

Senator WHITEHOUSE. Without objection.

Senator COLLINS. On a more personal level, just within the past few months, a very close friend of mine was a patient in the Gosnell Memorial Hospice House in southern Maine. I visited her twice there, and I had the opportunity to see firsthand what compassionate, high-quality, and seamlessly coordinated care can mean for patients with advanced illness and their family.

In most cases, hospice care enables dying patients to remain in the comfort of their homes, free from unnecessary pain and surrounded by family and friends. The Gosnell Memorial Hospice House, in Scarborough, Maine, provides an alternative for those individuals for whom care in their home is no longer possible or no longer sufficient. I just wish we had more hospice houses throughout the State of Maine and throughout this country.

This hospice house provides a comfortable homelike setting for hospice patients and their family in which they can receive advanced patient-centered care. From pain and symptom management, to psychological and spiritual support, to actually delivering longed-for scones to accompany my friend's tea, the care at Gosnell Memorial Hospice House was always centered on the patients' needs and desires, and it is first rate. And I've seen what a tremendous difference it has made and made for my friend, and for other patients and their families.

Again, thank you for having this hearing, and I know this issue is a personal passion for my colleague from Rhode Island, and it

is for me, also. This is an issue that I, too, have worked for many years on.

Finally, let me just end by saying the last area where we should be cutting Medicare reimbursements is for hospice and home-based care. That is such a poor decision, and I hope that's something that can unite us.

Thank you.

Senator WHITEHOUSE. Thank you, Senator Collins, and I can recall sitting in this committee and hearing you speak on the subject, and having the hair on my arms stand up, you spoke so eloquently about it. I'm very glad that you're here and your passion for this is, let's just say I'm a newcomer compared to you, and I appreciate what you said.

I would like to add a document of my own to the record, which is the "Wall Street Journal" article from February called, "Why Doctors Die Differently," which was a very interesting article showing how doctors who actually know better than anybody else how the system treats people at end of life so often make the decision that they're going to opt out of that particular treadmill and go out on their own terms and with their dignity intact. So, without objection, that will also be made part of the record.

And we've been joined by my distinguished colleague from West Virginia, Joe Manchin, and I would invite Senator Manchin to say a few words.

STATEMENT OF SENATOR JOE MANCHIN

Senator MANCHIN. Thank you, Senator Whitehouse. I appreciate very much your concern and your interest in having this hearing. And Chairman Kohl, thank you, again, for your courtesies as always.

In West Virginia, we have the second oldest State in the nation, percentage-wise, per capita, and so it's very near and dear to all of us. And we have one of the largest homeownerships. So, independent living. Our amber is Montani Semper Liberi. Mountaineers are always free, and trust me, they truly take that to heart, especially as we grow older.

When I was governor, our biggest concern we had is how do we allow people to live in the dignity and respect that they've earned all their life. I've watched so many of my friends' family members, their parents and their grandparents, their aunts or uncles that have gone into a nursing home, and truly have given up, because they've taken everything away from them. They took all their assets away and left them with nothing. And these were people that were proud making decisions all their life, helping their family, and all of a sudden everything was taken away. So, we thought there had to be a better way.

When I became governor, from 2005 to 2010, we expanded more services for in-home care, assisted, to help the people live, assistance, that could live independently. We spent more money than ever in the history of our State, and I think on a percentage, more than any other State in the nation. And we have more people living at home than ever before, and people that might, otherwise, be institutionalized.

So, that being said, I know this is a very tough decision. It's one that we keep putting off, especially those of us who don't want to face the inevitable that we might have to make these decisions. I have a few questions we'll go into later. I just want to make the statement that I appreciate your commitment towards helping all of us live with a little bit more dignity and respect as we grow older, but how do that as public policy.

And I know the States have an awful lot of involvement, if they want to. I have been committed that you base your priorities around your values, and if you have the values of taking care of your youth, taking care of their experienced citizens as they grow older, and the veterans who have given you the freedoms to enjoy all these things, then you'll be fine. And you can't do everything, I know that, but this is a value we hold very near and dear in West Virginia. I'm so pleased to so many of you involved in the same concerns that we have, and helping us is going to be tremendous.

So, I'll have some questions later. I thank you again, and I'm very proud of my State, and the things that we've done.

Senator WHITEHOUSE. Thank you, Senator.

Now, our first witness this afternoon is from my home State. He's Dr. Vince Mor. He's a Professor of Community Health at the Brown University School of Medicine. Dr. Mor has been on the faculty of Brown for, believe it or not, over 30 years. I guess he started young. He has served in a number of positions there, including as director of the Center for Gerontology and Healthcare Research, and chair of the Department of Community Health.

He's been principal investigator for nearly 30 different NIH research grants. He's been awarded grants from the Robert Wood Foundation and the Commonwealth Fund, as well as HCFA and the Office of the Assistant Secretary for Planning and Evaluation.

His research focuses on how different models of care influence healthcare use and the healthcare outcomes, particularly for frail and chronically ill individuals. He's also evaluated policies in aging and long-term care, including Medicare funding of Hospice, an issue Senator Collins mentioned, patient outcomes in nursing homes, and a national study of residential care facilities.

Dr. Mor, I extend you a warm welcome down to Washington, D.C., and I look forward to hearing your testimony.

**STATEMENT OF VINCE MOR, PH.D., FLORENCE PIRCE GRANT
PROFESSOR OF COMMUNITY HEALTH, WARREN ALBERT
SCHOOL OF MEDICINE, BROWN UNIVERSITY, PROVIDENCE,
RI**

Dr. MOR. Thank you very much. Good afternoon, Senators. I want to thank you for the honor of speaking with you today regarding the critical needs of people who are dying and their families here in America. Actually, Senator Kohl, I could probably put everything away, because you prefaced most of my comments, as did Senator Collins.

About 2.4 million Americans die each year, and for them dying is a critical event. Obviously, in the life of a family, that without appropriate medical care and support can result not only in pain and suffering for the dying person, but post-traumatic stress and complicated grief for survivors, as Senator Whitehouse indicated.

My charge today is to talk about the context of dying in America. Over the past 3 decades we've made great progress in the U.S., with the expansion of hospice services and the emerging subspecialty of hospice and palliative medicine, but very important work remains to be done.

Our healthcare system is still a long way from ensuring that medical care at the end of life is based on the patients' fully informed preferences and values. Successes in public health, and medical treatments, and chronic disease have resulted in tremendous increases in longevity. Over the past century the average number of years a 75-year-old can expect to live ticked up just a bit ever year. So, increasingly we encounter centenarians, the fastest growing part of the population of those 85 and over, and the older population is dying of diseases that a century ago were extremely rare.

Dementia, despite not being recognized a terminal illness several years ago, is now the sixth leading cause of death in the United States, and 1 in 8 Americans 65 and over is afflicted with it. All these patients have a different dying trajectory than patients with cancer, for example. They have the same needs for symptom management. Pneumonia in a patient with dementia results in the same level of shortness of breath as it does in a cancer patient.

So, based on our research and that of others, the place of care and the geographic region, you mentioned Wisconsin, greatly influence how they die and where they die. In a study we conducted of survivors of individuals who had been in a nursing home in their last weeks of life, we found that 1 in 3 reported that their loved ones experienced inadequate pain control, they did not have enough emotional support, and that they weren't treated with dignity. On the other hand, among those who died at home and with hospice services, nearly 71 percent rated the care of their loved one as excellent.

Since more and more Americans are spending part of their last weeks of life in a nursing home, this has implications that go far beyond the people who live in nursing homes on a long-term basis, because they're moving through these facilities. Sadly, too often, dying persons and their families are lost in transition between acute care and nursing home. With funding from the National Institute on Aging, I have worked on a multidisciplinary research team that includes Dr. Joan Teno, to describe the pattern of transitions at the end of life amongst nursing home residents with advanced cognitive and functional impairment.

We created an index of burdensome transition and found that there is a huge geographic variation in the likelihood that people experience these burdens and transitions in the last month of life. We compared Grand Junction, Colorado, and McAllen, Texas. And if you were in Grand Junction, Colorado, only 13 percent of the dying patients had one of these burdensome transitions in the last month, whereas more than twice as many in McAllen, Texas, had them. In Wisconsin, it's almost as low as in Grand Junction. High rates of transition from one medical care setting to another result in medical errors, problematic care coordination, duplication of services, and relocation stress for these frail older persons.

So, what I'd like to do is make a few recommendations. First, it must be clear that a single healthcare provider or healthcare system should be accountable for an episode of care. We should no longer tolerate the sentiment that some have expressed, "out of my hospital, no longer my responsibility". Hospitals, nursing homes, and other healthcare providers must become partners in order to decrease inappropriate healthcare transitions, particularly in the last month of life.

Financial incentives, whether it's bundling payments, or some other mechanism, have got to be aligned to make this possible. Without financial and clinical accountability, dying patients and their families will continue to be lost in transition. If we do this, we have to make sure that incentives to go in one direction aren't countermanded by having other incentives going in the other direction of denying care. So, we have to ensure that managed care or other organizations are held accountable for providing care consistent with patients' preferences.

Currently, in 2012, Medicare is the predominant payer for older populations. The fee-for-service system that we have in place now, which made sense in the 1960s when we designed it, to increase access for older people who didn't have such care, doesn't make sense now. Fee-for-service payments, create separate silos for funding each type of provider such that they are only concerned with what goes on inside their walls. We believe it's essential to move the current system towards increased accountability, whether it's managed care or accountable care, something has to be done to bring these together. Otherwise, I worry that frail elderly individuals will continue to be transferred from one provider to another, like so much flotsam and jetsam.

Thank you very much for your time.

Senator WHITEHOUSE. Thank you, Dr. Mor.

Our next witness is Dr. Gail Austin Cooney. She is the Associate Medical Director for Physician Quality and Performance Improvement at Hospice of Palm Beach County, in Florida. In 2005, Dr. Cooney was diagnosed with metastatic ovarian cancer, which recurred in 2010. Both times, Dr. Cooney received curative and palliative care concurrently. Today, her cancer is, again, in remission.

Hospice of Palm Beach County is a non-profit hospice facility that provides care for approximately 1,200 patients daily, in a range of settings, including private homes, hospitals, nursing facilities, and assisted living facilities.

In 2009 to 2010, Dr. Cooney was president of the American Academy of Hospice and Palliative Medicine. In 2012, she received that organization's Josephina D. Magno Distinguished Hospice Physician award.

Dr. Cooney received her medical degree from the Mayo Medical School, completed residencies in internal medicine and neurology at Emory University, and completed a neuro-oncology fellowship at Memorial Sloan Kettering Cancer Center in New York.

Dr. Cooney, we are already wowed by you and look forward to hearing your testimony.

[Laughter.]

STATEMENT OF GAIL AUSTIN COONEY, M.D., ASSOCIATE MEDICAL DIRECTOR FOR PHYSICIAN QUALITY AND PERFORMANCE DEVELOPMENT, HOSPICE OF PALM BEACH COUNTY, WEST PALM BEACH, FL

Dr. COONEY. Senator Kohl, Senator Whitehouse, and other distinguished members of the committee, thank you so much for having me here to speak today.

As was discussed I spent most of my professional career in the field of hospice and palliative medicine. And Senator Collins, when you mentioned patient-centered care, it made me realize that that is why I have been so happy in my field, because that's what I found there.

But I'm going to mostly talk today about my personal story, because a few years back I had an unusual meeting of my personal and professional lives, and I know that I would not be here today to speak to you without the support of my palliative care team.

I'd like to give you a definition of palliative care, because it's often very misunderstood, both by the general public and by healthcare providers. Palliative care is specialized medical care for people with serious illness. This type of care is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness, whatever the diagnosis. The goal is to improve quality of life for both the patient and the family.

Palliative care is provided by a team of doctors, nurses, and other specialists who work along with the patient's other doctor, to provide an extra layer of support. Palliative care is appropriate at any age, with any diagnosis, at any stage of the illness, and can be provided along with curative care. For me, the key messages in my story are that focus on quality of life, while pursuing curative treatments, because that's what happened to me.

In 2008, I was actually developing a palliative oncology program in West Palm Beach, Florida, where I live. Things were going well. We were due to open in August of 2008. But on July 27th, I walked into the office of one of the oncologists that I was working with—you know, I'm a doctor, I didn't make a doctor's appointment—I just walked into the office, and I said, "People have told me that I'm bloated." And she looked at me and said, "Not bloated." I had an ultrasound. I had a CAT scan. And by that afternoon, I had been diagnosed with stage IIIC ovarian cancer. That's the stage at which most women are diagnosed with ovarian cancer, because it is almost always diagnosed late. But I don't have time to tell you all about that today.

Two days later, I had surgery. It is difficult surgery, because of the way ovarian cancer spreads. It is like you take a black velvet painting and throw a carton of yogurt at it, and then go in and try to clean it up. The surgeon does the best he can, but there's still stuff stuck in between all of those "little black velvet fibers." And so the second part of treatment, after the surgery, is intraperitoneal chemotherapy. And what that means is that they take some of their most toxic drugs and dump them right into your belly, with the idea being that it will get right up against those tumor cells, up in the black velvet, and be able to get rid of them. It's very toxic therapy. Only about 40 percent of women who begin a course of intraperitoneal therapy are able to complete it, because

of the toxicities. But of those women that do complete the therapy, a third live over a year. And for ovarian cancer, that is good.

I decided I wanted to be one of those third. But if I was going to do it, I had to make sure that I could tolerate the side effects of the treatment, and that's where I knew to ask for the help of a palliative care team. And so I actually became one of the first patients at the palliative program I had just been setting up. It's a strange life.

My team worked on the nausea and the vomiting; the chemotherapy is very toxic that way. I used medications. I had acupuncture. The other really difficult problem is the communication between family members. I can talk to my patients about advanced illnesses. But, talking to my husband and my children, I needed guidance. I worked with a counselor on those issues. And I hung in there. On Christmas Eve 2008, I had my last treatment.

Two months later, I was in remission. I started feeling better. My hair grew back. I even started working part time. But even though I was feeling well two years later, in 2010, the cancer came back. I had no symptoms this time, but it was back. And the choices for treatment this time were even more complicated. On initial diagnosis, it is somewhat straightforward what you do first to treat cancer. For recurrences, they often don't have as much data. And even though I speak doctor pretty well, pretty fluently, I needed somebody to help me talk through what my goals of care were, as I looked at a whole new range of toxic therapies. Again, I needed my palliative care team.

I ultimately had chemotherapy. After that, I had surgery at M.D. Anderson Cancer Center, in Houston, Texas, where I also accessed their palliative care team. It was a tough year. But, I'm happy to say that once again my disease is in remission, and I have been left with a real passion to share my story, because I think it is so important that people understand the benefits that palliative care can have when it's used from the time of diagnosis, because for many serious illnesses, the treatments are difficult. And for me, my palliative care team helped me to make the side effects a priority. They made sure that treatment of side effects was a priority. They helped me to talk about the issues that otherwise would have just been underlying stressors that would have made it more difficult to heal. I really want others to have access to this kind of care, because as difficult as my experience was, I had a lot of things going on my side.

I have a husband and a family who love me and stood by me. I have good health insurance, and I didn't have to bankrupt my family in order to pay for my medical care. I had access to superb palliative care and I knew to ask for it; because even where I was, in some really good institutions, I had to ask for palliative care, and most people don't know to ask.

People with serious illness, me now, and someday all of us, we need your help to make this kind of care, this added layer of support, available to all Americans, so that they can have an experience with serious illness that is as healing and as hopeful as mine has been.

Thank you so much for listening to my story.

Senator WHITEHOUSE. Thank you so much, Dr. Cooney.

Our third witness is Karren Weichert. She's the President and Chief Executive Officer of Midland Care Connection, in Topeka, Kansas. Over two decades, Ms. Weichert has transformed Midland Care from a volunteer hospice program into an integrated care delivery system that offers services across the continuum of care.

Under her leadership, Midland Care opened the first hospice inpatient unit, the first hospice-sponsored adult care facility, and the first hospice-sponsored PACE program in Kansas.

In addition to her work at Midland Care, Dr. Weichert has served two terms as national director for the National Hospice and Palliative Care Organization, and currently serves on their governance committee. She also works with Leading Age, as a member of the Hospice Home Health Taskforce, and is a board member of the National PACE Association, and chairperson of their Public Policy Committee.

Ms. Weichert, I appreciate coming in today. We're delighted to hear your testimony.

**STATEMENT OF KARREN WEICHERT, PRESIDENT AND CEO,
MIDLAND CARE CONNECTION, INC., TOPEKA, KS**

Ms. WEICHERT. Thank you. Chairman Kohl, Senator Whitehouse, and members of the committee, I am really delighted and quite honored to be with you today. I am Karren Weichert, with Midland Care Connection, Topeka, Kansas. And as the Senator said, we started with the hospice over 30 years ago, and now have developed into a full continuum of care services to address the needs of those with advanced illnesses.

Our continuum today includes not only hospice inpatient care, as well as homecare, but it also includes adult daycare and residential care, home health, home support, a palliative care program, and PACE, Program of All Inclusive Care for the elderly.

I want to tell you a story about a gentleman who was in our care a couple of years ago, Denzel Ekey. And Denzel came to us as a 78-year old man with Alzheimer's disease and myasthenia gravis, which affects the muscles in his arms and legs, and eventually his throat.

He was cared for by his wife, Mary, in the home, and she was doing an outstanding job of that, but she needed some help. And so she invited us into help with his personal care, bathing and such. We did that for a short time, and then he began to coming to our adult daycare. As his care needs continued to increase, and it began to be more difficult for her to provide that care, he was enrolled in our PACE program, whereby we could wrap services around him, coordinating not only all of his medical care, but all of the supportive care needs that he had while remaining in his own home.

Eventually, because of his disease process, and some of the things that his wife encountered, he had to move into our residential center, and we were delighted that we had that option for him, because there he was still connected with his PACE team, the residential team was there to provide him that 24/7 care that he needed to maintain, and then at some point, when the PACE team recognized that he actually was in the last few months of his life, they actually invited the hospice colleagues to be involved in his care as

well, because there were some complexities to his care that they needed assistance with the symptom management of his disease process.

The hospice team also lent a hand to Mary, and she was a devoted wife, and she needed help just dealing with the fact that she was going to be losing this man that she had loved all these years. She came every day to the residential center and sat by his side. And, in fact, she was with him on that last day, Christmas Day of 2010, and he died.

I tell this story, because Denzel was so near and dear to us as an organization, because he sat on our board over 25 years ago when we were just a hospice, when we had a dream to develop into something more, and he was one of those people with courage and conviction that stepped out and said, yes, I think we need to do this. We need to make some decisions that can move our organization forward and serve more people. And we did that. Little did he know that we would one day be serving him. So, we were honored that we had that opportunity.

Denzel is also significant, because he's one of those over age 65 afflicted with Alzheimer's that we've heard. And Alzheimer's today is one of the top 10 diseases in our country, but it is one for which there is no prevention, there is no cure, and there is no way to really successfully prevent the progression of the disease. So, it's very significant that we should talk about Denzel today.

I also want to talk about how does all of this care happen. I believe that as we look ahead at how we might be forging a new way to provide care, and we've heard some really poignant and significant statistics today about how we can provide care to those with advanced care illness. I think it's important to remember that it needs to be provider based, and by provider based, I mean that it needs to be an entity who is responsible not only to coordinate the care and to manage the care, but to provide the care.

It also needs to be interdisciplinary in nature. It is extremely important that the whole team be involved in the care of a significant illness, because it is not just a physical process. It affects the whole person, and the interdisciplinary team comes together, as professionals, to work on all of the different elements that might be affecting the patient through this process.

It also needs to take into account that one person has the disease, but the whole family is going through this process, and we certainly need to build into our system ways to support those caregivers, because they are so critical to the effective care of individuals who want to remain in their home.

And lastly, I think that those organizations need to have financial responsibility and be accountable for the care that they deliver. We have in this country two programs, both PACE and hospice, who have been doing this for a number of decades now, and they are capitated systems. They're given a set amount of money, and then they are required to provide all of the care that the individuals entrust to them must have. And they do, and they do it quite effectively, and they do it with a high satisfaction rate throughout our country.

Today, we are challenged with silos. Silos in our healthcare system, providers not communicating very well with each other, and

patients caught up in those silos. We also have silos in our regulatory entities, and we have regulations that are quite antiquated, and not effective in today's system, because today we have ways to communicate that we didn't have 20 years ago, when many of those regulations were developed.

We have electronic medical records. We have real-time reports about what's going on with our patients. Much more effective ways to serve them, and yet, many times, we are mired down in all of the regulatory things that we have to meet. If we are to serve people effectively, we need to eliminate some of those silos and mesh those together, so that our focus can be really on delivering that care.

I think in this country these two programs have also been effective for three reasons. First of all, because they both developed around helping patients to stay in their home, stay in their home, where they want to be. They also developed with those patients as a part and as a center of the care, involving them in the discussions about what was happening to them, educating them about the process of their disease, and having them have input into what was going to happen.

They've also utilized that interdisciplinary team, which is so important, because we understand in hospice and in PACE that suffering is not just physical pain. It happens to us in totality, and so we have to learn to serve that total person. And we've also learned that, I think the reason that hospice and PACE have been so effective, and probably one of the key things that have cut down on ER visits and unnecessary hospitalizations is because they are responsive. They are available 24/7. They answer that telephone. They calm those fears. They go and sit by the bedside. And they make those home visits at 2:00 o'clock in the morning, either the physician, or the nurse, someone is going out there. And that avoids those unnecessary stays in the hospital.

I will tell you, we don't like people to go to the hospital. A couple of reasons. We're financially responsible for that. That's one of them. But, you know what, it goes far beyond that. Hospitals are not great places to be. If you've ever been to one of them, there's a lot of sick people there, and we have a very frail population that we then are exposing to a lot of other things. We don't want them to go to the hospital. And it's very disorienting. We want them to be at home, if at all possible.

I encourage this committee and Congress to use these programs as the models. We have a lot of new innovative programs being talked about out there today, but we've got two programs in this country that have been around, that have been effective, and are underutilized. And I would submit that we need to build on that which we know is effective and that which we know has those components that people are asking for today.

I appreciate the opportunity to be with you today. I think that we have a big charge ahead of us to develop a program and in a healthcare system that's going to serve people with advanced illness. It needs to be seamless. It needs to be coordinated. And it needs to have the patient at the center of the care.

Thank you.

Senator WHITEHOUSE. Thank you. Well, we appreciate the opportunity of you sharing your experience with us. So, thank you very much, Ms. Weichert.

Our final witness is Albert Gutierrez. He's the president and CEO of Saint Joseph Regional Medical Center, in Northern Central Indiana. Mr. Gutierrez joined Saint Joseph in 2010. It's a multi-hospital, non-profit healthcare system that includes acute care hospitals, a rehabilitation center, 20 in-network physician practices, and several community health centers. It is a ministry organization of the fourth largest Catholic healthcare system in the country, Trinity Health.

Saint Joseph has been recognized as one of the top healthcare systems in the country, having been named one of the top 15 hospital systems in the nation by Thomas Reuters. This year "Modern Healthcare" magazine named Mr. Gutierrez one of the country's top 25 minority executives. Prior to joining Saint Joseph, Mr. Gutierrez was president and CEO of Shore Memorial Hospital, in New Jersey, where he was employed for 25 years.

Mr. Gutierrez earned his bachelor's degree from Thomas Edison State College and an executive MBA from Saint Joseph's University. Me. Gutierrez, we are delighted you're here. Please proceed with your testimony.

**STATEMENT OF ALBERT GUTIERREZ, PRESIDENT AND CEO,
SAINT JOSEPH REGIONAL MEDICAL CENTER, MISHAWAKA, IN**

Mr. GUTIERREZ. Thank you very much, Senator. Distinguished members of the committee, colleagues in healthcare, members of the public, and my fellow panelists, for the purposes of these proceedings, my perspective is one of a healthcare executive. While we have angels in the architecture, saving our patients in hospitals, I'm the direct intermediary to the funding sources and the Federal Government.

We believe that there are specific structural elements related to empowering patients and honoring individual decisions in care. The first prescription is a prescription of hope for the suffering. Part of the wide variation in treatment modalities for suffering and its related expressions is the wide variability in individual's tolerance to suffering. The tolerance of the patient, but also the tolerance of the loved ones who are watching the person suffer.

Suffering occurs when one is deprived of clinical and emotional support. When we observe suffering in another human being, God gives us all the remarkable reflexive response to preserve life. I'm sure the committee has witnessed this behavior in the selfless heroism of our soldiers on the battlefield and the individuals who rushed to help those who are injured or afraid at Ground Zero, among innumerable other examples. This instinct to help a fellow human being is remarkable. Countless times every day it occurs in our healthcare facilities. This natural instinct to help and heal arises in compassionate caregivers who receive the suffering at our doors.

Unfortunately, in pursuit of a noble goal, relief of suffering, we frequently offer ineffective, costly, and painful procedures, sometimes to the detriment of the economic stability of our own institutions and the economic instability of our country. We actually know

what patients want in advanced illness. They want us to minimize their pain, reduce the burden on their families, and give them some control over what is happening.

Caring for the body, mind, and spirit of every person we touch is core to our mission, and is embedded in the walls of every health system within Trinity Health. As a ministry of the Catholic Church, we believe that every human life is worth living. Palliative care reflects our commitment to respecting the dignity of every human person. We believe palliative care to be a prescription of hope for suffering.

So, that being said, what is a prescription of hope for society? Good medicine is ethical medicine, and good medicine yields high-quality, cost-effective outcomes. What is truly amazing about palliative care is that while it alleviates suffering for the patient and family, it does improve the quality of care and reduce costs. We know that the extensive use of healthcare resources does not enhance the quality of life at the end of these precious lifetimes. Patients should know they have a choice. They have a right to forego costly, burdensome, extraordinary, or disproportionate interventions.

So, what happens? In order for a patient to make sound decisions within those parameters they must be engaged in the conversation. Senator Whitehouse, as you mentioned earlier, when we have failed the request of patients, what is it that has occurred? I can only articulate my conversation with my father, who loved three things: His family, his God, and the New York Yankees, who had a son who is the president of a healthcare system, who had access to some of the best physicians and treatment modalities in the world. And he was very specific to me. He said, "Son, I'm finished. I've done everything that I've wanted to do in life. Do not use any of your abilities and skills to save my life. I am ready." So, we sat down and we documented the event, and we put the information, and I gave it to my parents, and it was all set.

My father died in my sister's arms, but still I get the call from my sister, as the ambulance is rushing to the house, "Where are the documents?" And we could talk about solutions for that a little bit later. But, in order for a patient to make sound decisions within those parameters, they must be engaged in that conversation.

As a faith-based institution, we also believe in the prescription for hope for each precious life. At the core of our prescription for hope is establishing that conversation and making sure that we engage the role of our faith-based agendas as we all see them as individuals. It is even made more difficult when people have no hope and have no particular perspective on faith, and still, health systems need to be a part of that conversation.

At our facility, a 60-year-old man who had suffered a massive stroke showed up alone at our emergency room. After CAT scans and other examinations, the doctors agreed that that massive stroke was so damaging that he would not recover. Someone called the only number on his cell phone contact list. It said, "Boss." And there were no other contacts. Our legal staff exerted every effort to locate next of kin, even getting permission to search his apartment for an address book, to no avail.

The doctors had determined that the curative line of care was not possible, and his boss was not willing to take the responsibility of serving as his guardian. We convened our ethics conference, and based upon our proceedings, we brought our recommendation to the courts, and a judge appointed a guardian.

After extensive discussion, the guardian and the doctors clearly understood the medical choices. And in the best interest of the patient, extraordinary interventions were ceased and he was moved to hospice care.

There, the guardian visited him on a regular basis. The one documentation of his wishes that we did find was he wanted to identify himself as an organ donor. Saint Joseph's Regional Medical Center, upon his passing, met his wishes, paid his funeral expenses, and had him buried in a local cemetery. The patient died with dignity, with his desires being met.

So, in light of my closing recommendations, as a Catholic institution, we are committed to caring for every person who comes through our doors and to make sure that that commitment is sustainable. We have long encouraged these conversations. Going back to the Civil War, the Sisters of the Holy Cross, in South Bend, took care of the injured and dying on both sides of the armed conflict. So, therefore, first, we need to ensure that palliative care programs and providers are in place across our country, and are well funded.

Second, we need to shine a light into end-of-life care as a societal issue to be addressed. No longer should it remain in the shadows. It's no longer enough just to ask if there is an advance directive. It's more for everyone to understand what's in the directive.

To that end, recently, our community needs assessment identified a very simple tool. It's called ICE, in case of emergency. And where do you find ice? In a refrigerator. So, I've learned with discussions with every family member to put our documents in a tube and put them in the refrigerator, and put a symbol on the door. And that's part of the deployment that we'll be having in our particular community over the next year. Too long has our country shied away from these difficult conversations.

Third, we need to establish the guarantee that no one dies alone. Just as we saw with the end of life care given to a stranger, no one should face that end of life alone.

My last directive comes to us as a people from a letter of his Holiness, Pope John Paul, to the elderly in 1999. A letter that should be given to every senior in the country. That's pretty specific. And Pope John closes in a way that I should close today. And he writes, "And when the moment our definitive passage comes, grant that we may face it with serenity, without regret for what we shall leave behind, for in meeting you, after sought you for so long, you'll find God. We shall find once more every authentic good which we have known here on earth, in the company of all who have gone before us, marked with the sign of faith and hope." And I'll get to see a Yankee game someday.

Thank you very much.

Senator WHITEHOUSE. Thank you very much, Mr. Gutierrez. That was wonderful, moving, impressive testimony from all of you, and I thank the panel so much.

I will turn first to my colleague from West Virginia, Senator Manchin, whose schedule is pressing, and allow him to ask his questions.

Senator MANCHIN. Thank you, Senator.

First of all, thank you all for moving testimonies, and I appreciate it very much.

Mr. Gutierrez, I would assume that your sister found the document, because your father died in her arms.

Mr. GUTIERREZ. Yes. When she called me, I said, "It's in the can on the shelf in the closet. And it was appropriately deployed, and yes, he died comfortably in her arms."

Senator MANCHIN. And your recommendation is, is that we go for ice. Is that what you mean?

Mr. GUTIERREZ. Absolutely. Go for ice in the refrigerator, and that's where the documents are, unless you're a member of the younger generation, we expect there will be an app to address that.

Senator MANCHIN. I assume there would be. I was thinking about that, thinking that, you know, with Facebook and everything else.

Mr. GUTIERREZ. You know, it's part of the overall recommendations. You'll see that coming from our South Bend study over the next few months.

Senator MANCHIN. Dr. Mor, I think in your testimony you said that people receiving hospice were receiving it too late, and I assume that we're keeping them in the hospital longer than what they would desire, or what good we can do there. And we should be getting them back into the care of their loving home, and have hospice intervene.

How do we do that? Is it just the rigmarole or it's the business of business, I guess I could say.

Dr. MOR. It's complicated. I think one of the issues is that not enough people have the conversation with their doctor about their prognosis early and often. I was really delighted that Mr. Gutierrez brought up this issue of the conversation.

It's also, as Karren mentioned, about the lack of continuity. People bounce from one place to the other, and the system just proceeds. It's also because there are these silos of both payment and accountability. Over the last decade, we've seen a doubling of the number of people who actually use the Medicare hospice benefit, but, there's also been a very substantial increase in the proportion of people who only get 3 days of hospice before dying. And half of those people have a prior hospitalization, including intensive care.

Senator MANCHIN. How long could hospice care, I mean how long could it be delivered?

Dr. MOR. Well, if people, for instance, are arriving 10, 15, 25 days before, it's not a building, but in care, then there's a reasonable process to deliver needed support and services. Even earlier, if there's advanced time, and depending on the nature of the disease, there's just more time to get the mix of services and symptom management right. And that's what's important.

Without the integration, without the conversations, there are too many people who fall in the cracks. It might be done properly in Wisconsin, or Minnesota, but it's not done properly often around the country.

Senator MANCHIN. And Ms. Weichert, a Medical Association study found that caregivers have access to patients' living wills as infrequently as 16 percent of the time. How does your organization make sure that we have care teams that understand the goals and wishes?

I go back to the early 1980s with my grandmother. And I had my grandfather die suddenly of a heart attack, and my grandmother, she died at the same time trying to help him. But, then 9 days had passed, and she was on life support. And we just knew that she wouldn't want to live a life like that, and eventually the whole family had to make this decision to make the hospital understand that's what we know that she would have wanted. But, 9 days had gone by.

I mean today's a different day. I understand that. How do we make sure? I heard that there were cases where the hospital still doesn't believe, and they still continue to do things when there's not a document.

Ms. WEICHERT. Well, I would say there's actually two things that I'd like to address in answer to that question. The first one is that in our care continuum, we have different touch points, where we have access to the patients and to the families, and we can have those conversations. The earlier someone accesses care, the easier it is to have those conversations.

And the second thing that I would say is that I'm a two-time cancer survivor myself. I know how tough it is to have that discussion when you are sick, when you are diagnosed. It is important for us to encourage our families to have those discussions much earlier, so that the other extended family knows what their wishes are, knows what they would like to have happen to them. So, if a time comes, as your grandmother, when she can't speak for herself, the family is confident that they're doing the right thing.

Senator MANCHIN. Right.

Ms. WEICHERT. One of the things that Mary said to me in my story about Denzel Ekey, she said, "Denzel and I had discussion long before, because we did not want our children to suffer through wondering if they had made the right decisions. So, we had that discussion, and we put those papers in place, so everyone would know what our desires were for our end-of-life care."

Senator MANCHIN. Thank you. My time is at the end, and Dr. Cooney, I enjoyed your testimony very much, and God bless you, and I wish you the best. And I know that better educating the patient is going to make a better informed decision.

What would you say, not everyone's going to have the opportunity to have the access you've had or the care you got.

Dr. COONEY. How do we improve access?

Senator MANCHIN. Yes. You had specific care, which was pretty extensive, I understand.

Dr. COONEY. Because I knew to ask for it.

Senator MANCHIN. That's it. Now, we're talking.

Dr. COONEY. You know, I think we need to educate the public, and I think we need to educate the healthcare providers, both, to see this as an integral part of medical care.

Senator MANCHIN. Thank you, Mr. Chairman. I appreciate it very much. Thank you. I'm so sorry I have to go to another meeting.

Senator WHITEHOUSE. Thank you, Senator Manchin. We're delighted that you could be with us.

I get you alone, now that everybody is gone. This is great. It means I don't have to obey my time limit.

[Laughter.]

Senator MANCHIN. I'm kind of afraid to leave.

[Laughter.]

Senator WHITEHOUSE. First, let me just thank you all again. This was a really superb panel, and I think it helps us make a wonderful record for pursuing action in this area. As I've been listening, I've been sort of trying to put the problems into different categories, and I've summarized the four categories as the transition, problem, lost in transitions, as Dr. Mor said, failures of directives, whether because they don't exist, or because they're not clear, or because they're not honored and given effect. The treatment of pain, and palliative care, and the conditions surrounding the underlying illness itself, and the question of family support and confidence in the proceedings, I guess.

Dr. Mor, you spoke very eloquently about the lost in transitions problem, and Ms. Weichert, you touched on it as well. I just wanted to let the other witnesses have an opportunity to touch on the transitions problems, if they cared to, where the handoff failures happen, and what we can do to minimize those transitions, where they're not absolutely necessary. And I'll put an asterisk on that question, because one of the things I'm pushing the Administration very hard to do is to take some of the meaningful use health information funds and create a pilot program, where qualified meaningful users will get the benefit of participating in the pilot, if they connect with nursing homes, which are not legally qualified, meaningful users. And that, I think, might help with some of the transitions that might be unnecessary. But, any thoughts that any of you have on the transition problem, I'd love to explore.

Mr. Gutierrez.

Mr. GUTIERREZ. Yes. Actually, at our facility we've narrowed it down to the specific document. We have a fully engaged, fully compliant electronic health record meeting all the requirements of meaningful use at this point. But, it's not the same standard that's applied for long-term care. So, we've identified the problem.

We have it down to one document, and that is the admission discharge and transfer document and its contents, and having the standards established that they all specifically address a full complement of understanding the medications that the patients are on, the clinical picture prior coming to the hospital. And if we were able to get more of that information on a consistent basis, the first orders that are written in the emergency room will be a much more effective bridge, instead of starting all over again. And that industry currently is underfunded significantly nationally to develop these electronic health records.

The second area, a bigger concern, with the——

Senator WHITEHOUSE. Just to jump in on that, in the future, my suspicion is, if we can get a pilot rolling on this, it would surely

prove that it actually saved money, and then we could extend the meaningful use program to nursing homes in line with the pilot without having to go and find a pay for, because, frankly, it would pay for itself in the improved outcomes and less unnecessary wasteful care.

Mr. GUTIERREZ. Yes. You are correct. What we've been finding in all the wealth of data that the electronic health record requirements have been giving us, that we're finding more and more opportunities to reduce costs. The data is actually magnificent. But not having access to the wealth of data that's created in that industry eliminates a lot of the expense in those first 12 hours of care, in particular in the emergency room.

So, I think your suggestion is something that we, as an industry, at least within our healthcare system, would find something that would help drive better communication, even within our own system.

Dr. COONEY. I'd just like to mention one of the ways in which a palliative care program can also help with transitions of care, because what they often do is serve as a communicator between the silos that exist in our healthcare system. I remember one patient on whom I was asked to consult on who was in the ICU and each doctor was addressing their own little body system. You know, their own little body system, wasn't doing too badly, but the woman was dying. I sat down and I wrote my note. I wrote, "Patient dying." One by one, they all came by and wrote, "Agree with above. Will stop - whatever their treatment was." Sometimes palliative care can help to serve that role of facilitating communication between the silos.

Senator WHITEHOUSE. The issue of failure of directives is one that I think is particularly concerning. First of all, we have the societal failure that many people don't have directives. And unfortunately, the whole fantasy about death panels emerged out of a very sensitive amendment proposed by actually a Republican colleague of mine, to simply provide for folks on Medicare to have a discussion with their doctor about what they wanted, so you could begin to make sure that there were, in fact, directives, and your wishes were, in fact, expressed and on record. I guess things can turn into strange political transmutations. But, it was a very, very sensible point. So, that's the first problem.

Then, you get to the problem of, as you said, Dr. Cooney, speaking doctor. These are very often written by lawyers, and they don't translate readily onto the hospital floor.

And then in the case in my family that I referred to, everything had been done, everything had been done properly, but unbeknownst to this wonderful woman, EMTs were forbidden to honor anything in the State where she died. You could have your priest, and your lawyer, and your accountant, and your family, and your advance directive, and your living will all right there, and they would come and resuscitate, because that's what they're obliged to do, unless you had a magic ribbon on your wrist. But, nobody had told her that she should have that magic ribbon on her wrist, plus she was a lady of a certain amount of elegance and style, and the last thing she would want was some ribbon on her wrist all day

in and out. So, there would have been a brawl about it, if that had been the option.

So, there are all these failings in the existence of them, in the comprehensibility of them, in the actual effect, when people think they've got them squared away. And Mr. Gutierrez pointed out, it's no good if you can't find it when you need it.

So, what are the best practices you've seen out there for coping with this? I know Gunderson Lutheran has worked hard on this. What do you see as best practices with respect to preserving and honoring wishes?

Dr. COONEY. I was really excited by the legislation that came out that eventually got shot down by the "death panel" people. I've always worried that attorneys write advance directives. The advance directives get filed away with the will. Nobody ever looks at them, and nobody knows what they say. In reality, it should be healthcare providers, ideally, the physician, but at least a healthcare worker, who talks through these issues with each person, because healthcare providers know the kinds of situations that that person is likely to run into.

The kind of complications I'm going to run into are different than the kind of complications that you're going to run into, because I have specific medical conditions. And an advance directive can be specific to those sorts of issues.

The advice I give everyone is to talk about their wishes with everybody they can, so that you have as many people as possible who know what you want, and will stand up for you. It doesn't get rid of the problem with the EMTs. I've seen that myself.

Senator WHITEHOUSE. Yes.

Dr. COONEY. The more people who know what you want, and that it is really what you want, and not something you just wrote down on a piece of paper in your attorney's office, when you were just signing documents, I think the better the chance that someone will stand up for you and make sure your wishes are enforced.

Senator WHITEHOUSE. Well, that's a very helpful thought.

Now, on the question of palliative care and treatment of pain, are we seeing better outcomes than we did when Dr. Teno did her first work, and what can we do to improve further?

I mean it's conceptually possible that we could have no one die in pain in the country, is it not? I know that in the case of my father, he felt very good about all of this, both because he had a nebulizer that was delivering his painkiller to him whenever he wanted it, and it was very effective. And he controlled the button.

So, he found he actually didn't need it very much. He'd been a marine. He'd been, you know, he was a pretty tough guy, but he really wanted to know that if he was going to need it, it was there for him. And so, that was very successful. And then, also, he had confidence in the hospice nurses around him, that if something happened, he could cope. So, his anxiety level about the whole operation, even though it was his imminent death, was actually pretty low. He felt he was in the hands of capable trained professionals. He knew he had a way to deal with pain. Let's bring on the rest of it. He was able to face it with a lot of calm. And I think that actually helps in the pain circuit as well.

But, Dr. Mor, you've done a lot of looking at this. What do you—

Dr. MOR. So, others could chime in, but my mother died here in Washington 33 years ago of cancer, and as was the practice in those days, she was down at the end of the hall, as far away from the nursing station as possible, and in pretty constant pain. Things have improved dramatically since that time, with patient-initiated analgesia, and a general sensitivity at all levels, and in most of the specialties in that medicine.

It's not to say that it's always done right, or it's not to say that it isn't sometimes done excessively, because for every action, there's sometimes reaction. But the constant awareness of pain, and the reported pain levels for people who are in their final weeks or months of life has dropped empirically, dramatically.

There are still other issues to deal with, but I think that our attention to pain as a sort of a sixth vital sign, as it were, has actually been very, very effective over time.

Senator WHITEHOUSE. It's actually reported in Rhode Island now as a vital sign.

Dr. MOR. It's reported as a vital sign. It's actually being reported as a quality measure for most hospitals, for hospices, for nursing homes, and for home health agencies. And whether the reports are exactly right or not right is not the issue, but it means everybody is attending to it and trying.

Senator WHITEHOUSE. Yes. Ms. Weichert, would you agree?

Ms. WEICHERT. Well, I do have a comment about that.

Senator WHITEHOUSE. Please.

Ms. WEICHERT. Thank you for asking me, but, again, isn't it interesting how we're all intertwined with our personal experiences. But, my grandson was diagnosed with Ewing Sarcoma, which is a cancer that hits children. And he was served in a regional hospital that just prior to his surgery, where they were going to amputate his leg, after a year of very aggressive chemotherapy, he was in significant pain, significant pain, and they couldn't seem to get it under control, nor did they, in my opinion, try hard enough.

And so, I asked our palliative care team if they would become involved. And, in fact, they said, "Well, there is a palliative care team in that hospital. Why don't we call them?" And so, our physician called that palliative care team in the hospital, where he was, three floors down, and they were appalled that they had not been called before. The concern is, because he was a child, we didn't want to overmedicate him. Oh. Well, did we want him to hurt? And so, within a couple of hours they had his pain under control. Thank goodness.

So, I think that there is still a lack of acceptance, even among other healthcare providers, about what palliative care is and what it can provide in quality of life to the patient.

Senator WHITEHOUSE. It strikes me that there are circumstances in which, although we silo conceptually curative care from palliative care, that there are nevertheless circumstances in which well-delivered palliative care has a significant curative effect. Is that the experience?

Ms. WEICHERT. Oh. I would say absolutely, Senator. And I think that they definitely go hand in hand.

Senator WHITEHOUSE. Okay. That one was unanimous.

And the last point that I'll touch on is this question of family support. Even to the extent that we're getting better at treating the patient with advanced illness, and trying to improve the directives that help that patient control how they'll be treated in their advanced illness, particularly in a very advanced illness, the family tends to be involved.

You've touched on the question of when there's no advance directive, then there's confusion, there's family stress, different family members are disagreeing about how much care to do, and you're in for a real mess. I think it was you, Mr. Gutierrez, who pointed out that having a solid directive lifted that burden off of the rest of the family, and was a good, you know, reason for people to get this done in their own lives, so they're not causing that stress among their loved ones.

But, I think, Dr. Cooney, Ms. Weichert, you were talking a little bit more about actually trying to provide support for the family in getting through this, and that that, in turn, provided benefit back into the care process. Would you want to address that a little?

Again, put it in terms of best practices. If you were going to design a program that had best practices, what would be the best practice for attending to the family of the person in the state of advanced illness?

Dr. COONEY. As you pointed out, Senator, just as a patient's death doesn't happen in isolation, it affects the family that lives on. A significant illness doesn't happen in isolation. It affects everyone who is around them. And yet, our healthcare payment system is very patient focused. The hospice Medicare benefit, you know, is directed at the patient and family.

I do a lot of work with physician billing, and you don't get paid for talking to the family. It's not considered an important part of your job. I think that's a huge mistake, because when we don't coordinate care for people in their individual context, we lose the opportunity to really deliver the best care to the patient, because their family is really part of that illness unit.

Senator WHITEHOUSE. Mr. Gutierrez. And then Ms. Weichert.

Mr. GUTIERREZ. Senator, the one intervention that is most appropriate dealing with the complexity of the medical information is the role of nurse navigation, having an individual who basically acts as a concierge to all the options, both on the moral, ethical, and scientific side.

We, unfortunately, cannot wait for, nor can the system afford for the right piece of legislation to come out. So, systems need to adopt, you know, the following three criteria that we're holding ourselves to. All patients and families, upon knowledge of a serious illness, must be made aware of the opportunity to have a palliative conversation. That's number one.

Number two, the professionals, all the professionals who are in contact with the patient during that serious illness, in their competency requirements, in their job descriptions, will have the competency to participate in an intervention and understand their role.

And third, that we need to find a way, irrespective of the payer's responsibilities, within our ministry, to provide an infrastructure that supports it on a consistent basis.

So, you know, the nurse navigator from our perspective is probably valued the most, because during that 15- or 20-minute physician interaction, or that ICU interaction, or that emergency room interaction, patients need more. And our investment in those individuals is something that is slowly evolving throughout all of our ministries.

Senator WHITEHOUSE. And the nurse navigator has responsibility for addressing not only the concerns of the patient, but also addressing the questions of the family.

Mr. GUTIERREZ. Absolutely. Usually, we're looking at individuals that are masters prepared. Whether they be oncology nurse navigators, or pediatric nurse navigators, usually having one assigned to a particular clinical service line is one that could be of a great assistance and guidance.

Senator WHITEHOUSE. And Ms. Weichert.

Ms. WEICHERT. Well, I totally agree with my colleague here. But, I would also say that when someone is given a serious diagnosis, someone that you love is given a serious diagnosis, most of us today run to the internet, and we look to see what is out there. And quite honestly, it's very confusing.

We also, the first place we go is, they're going to die, and what are we going to do, and how am I going to take care of them. It is the gift that we give one another when we are able to take care of somebody we love, and it's a gift that they give to us, but generally, we don't know how to do that, and we haven't been trained in that, and we don't know what to expect. And so, having those conversations very early on, having that opportunity for a palliative consult at the very beginning of a serious diagnosis, I think is critical to moving this issue forward in our country.

Senator WHITEHOUSE. Well, thank you. It's been a wonderful experience to share this panel with all of you. Your own experiences, as well as your dedication in this area, and your knowledge, has been immensely helpful. And I think that we're at a relatively primitive level, despite the fact that we're a very sophisticated society, in terms of how we deal with people with events, illnesses, how we support them and their families through the events they'll miss, and how we face and manage the process of death, when it comes.

And I think you've all been very helpful in helping this Senator and the others who were here make a record that we'll inform our decisions as we go forward, to try to provide more support to you and your excellent organizations, who are doing this out in the real world and with real patients.

So, I thank you very much for the time and trouble you took to come here and for the experience and wisdom that you shared. The record of these proceedings stays open for ordinarily a week, if anybody wishes to add any additional materials. And subject to that, the hearing is adjourned.

[Whereupon, at 3:25 p.m., the hearing was adjourned.]

APPENDIX

Vincent Mor, Ph.D.

The Florence Pirce Grant University Professor of Health Services, Policy and Practice

Warren Alpert School of Medicine, Brown University

Joan Teno, MD, MS.

Professor of Health Services Research, Policy and Practice

Warren Alpert School of Medicine, Brown University

Testimony for Senate Special Committee on Aging

Title: Trends in health services use among Medicare decedents

June 13, 2012

Good Morning, I want to thank you for the honor of speaking with you today regarding the critical needs of people who are dying and their families here in America. About 2.4 million Americans die each year. Dying is critical event in the life of a family that, without appropriate medical care and support, can result in not only pain and suffering for dying person, but post-traumatic stress and complicated grief for survivors. My charge today is to provide you with the context of dying in America.

Over the past three decades, we have made great progress in the US with the expansion of hospice services and the emerging subspecialty of Hospice and Palliative Medicine. Yet as I will outline for you today, there are important opportunities to improve care for the dying. Our health care system is still a long way from ensuring that medical care at the close of life is based on a patient's fully informed preferences and values.

Changing Demographics and Cause of Death

Successes in public health (e.g., through vaccinations that prevents disease, elimination of small pox) and medical treatments of chronic illnesses have resulted in tremendous increases in longevity. Over the last half century, each year as the Centers for Disease Control releases its new data, we find that the average number of years a 75 year old can expect to live has ticked up a bit. Increasingly, we encounter centenarians. The fastest growing segment of the population are those age 85 and older. Increasingly, this older population is dying of diseases that a century ago were rare; dementia, despite being

unrecognized as a terminal illness, is now the 6th leading cause of death in the USA and one in eight Americans 65 and over are afflicted with Dementia. While these patients have a different dying trajectory than a patient dying with cancer, they have the same needs for their end of life symptoms to be appropriately treated. Pneumonia in a patient with dementia results in the same level of shortness of breath as it does in a cancer patient. Simply stated, dyspnea from a lack of oxygen knows no difference between patients dying of cancer or those dying due to dementia.

Based on our research and that of others, the place of care and geographic region where people live greatly influence how and where they die. In a study we conducted of survivors of individuals who had been in a nursing home in their last weeks of life, found that about one in three reported that their loved one experienced inadequate pain control, that they did not have enough emotional support, and reported that they weren't treated with dignity. Only 42% rated the care their loved one received as excellent. In contrast, among those who died at home with hospice services, nearly 71% rated the care of their love one as excellent and only 3.8% stated that the care their loved one received did not always treat the patient with respect -- nearly 10 times lower than for those who died in a nursing home.¹ Since more and more Americans are spending part of their last weeks of life in a nursing home, this has implications that go far beyond the 1.5 million individuals in a US nursing home on any given day.

Sadly, too often dying persons and their families are "lost in transition" between an acute care hospital and nursing home. With funding from the National Institute of Aging,

(P01AG027296 and R01 AG024265), I have worked with a multi-disciplinary research team to describe the pattern of transitions at the end of life among NH residents with advanced cognitive and functional impairment.² We created an index of burdensome transitions based upon the number of times these individuals moved from one setting to another or changed the teams providing them care. We found that in 2007, nearly one in five NH residents with advanced dementia had a burdensome transition. To illustrate the striking geographic variation we observed, I contrast the pattern of these burdensome transitions in Grand Junction, CO and in McAllen, Texas:

Outcome	Grand Junction, CO	McAllen, TX
Multiple Hospitalizations for Pneumonia, UTI, dehydration in last month of life	0.5%	14.4%
One burdensome transition in last month	12.8%	27.1%
Two or more burdensome transitions in last month	0%	6.2%

High rates of transition from one medical setting to another result in medical errors, problematic care coordination, duplication of services, and relocation stress for these frail older persons. Indeed, the influence of geography and style of care is so pervasive that we

found in areas of the country in which seriously demented nursing home residents had higher than average rates of burdensome transitions, they were more likely to suffer a Stage IV decubitus ulcer in the last month of life, more likely to have an ICU stay, and to experience a late referral to hospice services. Unfortunately, we have little research to help explain why these geographic differences in treatment patterns even for very similar patients, are so stark.

As noted in the *NEJM* article contrasting the health care system of Grand Junction and McAllen,³ the financial incentives of the primary care physicians who run the Rocky Mountain Health Plan have financial incentives that are aligned to promote advance care planning and cost control. However, this area is still a rarity; there are too many areas like McAllen, Texas where transitions are common, uncoordinated, and it is the patients and their families who pay the price.

Indeed, our new research characterizing changes in the site of death, place of care, and health care transitions provides evidence of health care “non-systems” characterized by “more and more” health care utilization at the end of life. While the Centers for Disease Control, using national death certificates, has reported that over the last decade, more elderly persons are dying at home, site of death only tells you where the person was at the moment of death. It does not characterize the health care transitions and patterns of medical care in the last months of life.

With funding from the National Institute of Aging, we examined the places of care and health care transitions among Medicare fee for service decedents between 2000 and 2009. We document that indeed more people were dying at home and nursing home and fewer died in hospital in 2009 relative to 2000, we also find an increase in ICU utilization, health care transitions in the last 72 hours of life, and the overall rate of medical setting to setting transitions in the last 90 days of life. Consistent with the “more and more” theme, the use of hospice doubled over the last decade, but 28% of those who used hospice at all, initiated hospice within 3 days of dying in 2009! About one-third of these late referrals were preceded by hospitalization with an ICU stay. Despite the increase in both the availability and use of hospice services, for far too many Medicare beneficiaries, hospice is simply “too late.”

Financial incentives in the current fee for service system are aligned to promote the provision of “more treatments and services” and NOT health care based on informed patient preferences. Honest and complete communication about patients’ and families’ goals of care too often occurs too late. Some attribute this to the presence of perverse financial incentives for more hospitalizations rather than open and frank communications between physicians, patients and families about the goals of care. Where it has happened, aligning the financial incentives and the innovative use of nurse practitioners in nursing home has resulted in fewer hospitalizations, longer survival, and improved quality of care. These are the incentives, combined with accountability, that we want to promote in health care reform so that the right care is delivered at the right time and in the right location.

Based on our own and our colleagues research, we propose the following recommendations for your consideration:

First, it must be clear that a single health care provider, or health care system, is accountable for an episode of care. We should no longer tolerate the sentiment some have expressed: “out of my hospital, no longer my responsibility.” Hospitals and nursing homes must become partners in order to decrease inappropriate health care transitions, particularly in the last months of life. Financial incentives, through bundling of payments or some other mechanism, must be aligned such that a health care system is responsible for an entire episode of care. Without financial and clinical accountability dying patients and their families will continue to be “lost in transition” between the acute care hospital and other health care providers, such as nursing homes, home health, etc.

Second, any changes in financial incentives that shift from incentives to provide “more” care to incentives to provide “less” care under bundled payment arrangements, must be accompanied by oversight to insure that patients and families wishes are honored and that needed care is provided. This could be done using public reporting or random audits informed by data. It important that health care institutions or managed care organizations are held accountable for providing care consistent with a patient preferences and values.

In 2012, Medicare is the predominate payer for an aging population. A fee for service reimbursement system made sense in the early 1960’s when the primary concern was to increase access to high quality medical services for the elderly who had generally

been without insurance. However, fee for service payments together with separate reimbursement models for hospitals, doctors, nursing homes and hospices has created health care silos with each type of provider concerned only what goes on within the walls of their system. We believe that it is essential to move the current system toward increased accountability, whether with managed care or accountable health care systems embracing all types of providers. Otherwise, I worry that frail elderly individuals will be transferred from one provider to another like so much flotsam and jetsam.

I thank you for the opportunity to speak with you today.

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**Statement by
Gail Austin Cooney MD FAAHPM
Associate Medical Director for Physician Quality and Performance Improvement
Hospice of Palm Beach County
West Palm Beach, FL
Before the Select Committee on Aging
U.S. Senate
June 13, 2012**

Hearing Title: "Empowering Patients and Honoring Individuals' Choices: Lessons in Improving Care for Individuals with Advanced Illness"

Good afternoon, Senator Whitehouse and distinguished Members of the Committee. Thank you for your time, and attention to my story. I am Dr. Gail Austin Cooney. I have spent most of my professional life as a physician working in the field of hospice and palliative medicine, on both a local and national level. Today, though, I am going to talk about my personal experiences as a patient receiving palliative medical care. I know that I would not be here today if it was not for the support of my palliative care team. Because this is a new concept for many people, I would like to begin by defining palliative care in a way that is most easily understood:

Palliative care is specialized medical care for people with serious illnesses. This type of care is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness - whatever the diagnosis. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient's other doctors to provide an extra layer of support. Palliative care is appropriate at any age, and at any stage in a serious illness, and can be provided together with curative treatment.

For me, the key message is that palliative care puts a focus on quality of life while pursuing curative treatments. Without excellent symptom control, education, and psychosocial support, I would not have been able to tolerate the treatments of my disease. Because I was able to tolerate the treatments, I am here to talk with you today – feeling as well as I look!

In 2008, I was asked to develop a palliative oncology program in West Palm Beach, FL, where I live. The program was scheduled to open in August. On the morning of July 27th, I walked into the office of one of the oncologists to ask her about the abdominal swelling I had noticed over the previous 2 weeks. Within hours, I found that I had Stage IIIC metastatic ovarian cancer. Two days later, I had extensive surgery to resect as much tumor as possible. The surgery is difficult. Ovarian cancer spreads wildly within the abdomen. I compare it to throwing a carton of yogurt at a black velvet painting, and then trying to clean it up.

I got through the surgery. My oncologist told me that I would next need intra-peritoneal chemotherapy. This involves injecting highly toxic chemotherapy into the abdominal cavity, trying to put the drug directly in contact with the remaining tumor in the abdomen – the remaining yogurt that's stuck to the black velvet. Only 40% of women are able to tolerate and complete this treatment. With it, about 1/3 of women survive for over one year. I wanted to be one of those women! But I knew that I would need help to tolerate the treatments.

Because of my professional experience, I knew that I needed the help of a palliative care team. Sadly, the value of palliative care delivered from the time of diagnosis is not well known to either the medical community or the general public. That is something I want to change, and it is why today's hearing is so important.

I actually became one of the first patients at the palliative program that I had just developed. My oncologist led my palliative care team. She is board certified in both oncology and hospice and palliative medicine. She helped me to develop a plan to control the symptoms, pain, and stress of my disease and of its treatment.

Nausea and vomiting were my biggest initial concern. Dr. McKeen prescribed medications to take – before, during, and after each treatment. She recommended acupuncture twice weekly, both for my nausea and to enhance my sense of wellbeing. My husband and I saw the team's psychotherapist and we learned how to talk about my disease with our children and how to support one another. We talked about our fears; I was afraid that I was going to die. I learned to take each day as it came.

As other problems arose, I had a structure to help address them. Even though I was a physician, I knew little about chemotherapy. Now, I had my palliative care team to help me identify solutions to the problems. I had my last chemotherapy on Christmas Eve in 2008. Two months later, my cancer was officially in remission.

Gradually, my strength returned, my hair grew back, and I went back to work, sharing my new perspective with the patients and families under my care.

And then, two years later, the cancer came back. I felt fine but it was back. My palliative care team again helped me to understand and sort out the treatment recommendations – chemotherapy, surgery, or both? In what order? I speak “doctor” and I still needed help to understand my options and my personal goals. This was even more difficult than my initial treatment decisions: with each recurrence, there is less and less “solid” data on what the next steps should be; the decisions become more and more dependent on the patient's personal goals. I needed help to sort those out.

Oddly, I know exactly what I want if I am dying; but figuring out what I want when I am living with a serious illness requiring complex treatment – I didn't know how to do that!

My husband and I decided on chemotherapy, possibly followed by surgery to “clean up” any residual tumor. This course of treatment lasted longer – 6 months – but because the chemotherapy was intravenous and not in my belly, it seemed like a piece of cake. I went back to my acupuncture physician, saw the oncology psychotherapist, and kept working. So far, so good.

Then there was the surgery: it didn't go quite as well. I had that surgery one year ago, on my 59th birthday. It's the last time that I will do that on my birthday! I had my surgery at MD Anderson Cancer Center, in Houston, by the best surgeons in the business. I still had problems. I developed infections and my kidneys shut down. I nearly died. Once again, I knew to ask for help. Luckily, I know some of the palliative medicine physicians at MD Anderson, so I called them up. They sorted out my pain. They helped both me and my husband to talk through our feelings about the complications I'd experienced. I made it home. I got sick again – more infections in my abdomen. But my local palliative care team was there again, too. This experience really shook me and my needs were even more spiritual than emotional. They helped me to find the resources I needed for support.

I am back at work again – still me, but different. With my patients and families, I have a new understanding of their needs and the difficult decisions they face. I also have a passion for sharing my experience with palliative care because I know that it is what people need when they are facing serious illness. I know this from personal experience.

As difficult as this journey has been I know I am lucky. I have a husband and family who love and stand by me. I have great health insurance and have not been bankrupted by this illness. And just as important, I have access to superb palliative care teams and expertise. Without their support I would not have been able to be here to talk to you today.

People with serious illness, me now and eventually each one of us- need your help to make this kind of care- this added layer of support- available to all Americans. To provide the Committee with additional information about palliative care I would like to submit in the hearing record an April 2012 National Institute for Health Care Management Expert Voices In Health Care Policy paper authored by Dr. Diane Meier, MD

Thank you, again, for making this discussion possible.

Written Testimony to Senate Special Committee on Aging

Karren Weichert

President/CEO, Midland Care Connection, Inc.

**“Empowering Patients and Honoring Individuals’ Choices:
Lessons in Improving Care for Individuals with Advanced Illness”**

June 13, 2012

At Midland Care Connection our mission is “meeting individual needs through innovative health care solutions”. Over the past 35 years we’ve developed a continuum of services that can serve people once or several times over the course of years. Services can be accessed at the time patients need them and increased as care needs dictate. Currently, we offer hospice (in home and inpatient care), palliative care, home health, home support, adult day care, Program of All-Inclusive Care of the Elderly (PACE), residential care and grief counseling services.

I have personally been involved with this work for more than 25 years, originally as a caregiver to my father, then as a member of the board of directors and for the past 22 years as an employee of Midland Care. My father was diagnosed 25 years ago with renal cell cancer and had extensive bone metastases throughout his body. His prognosis was six months to live which came with a referral to hospice. He lived for 18 months and died at the age of 56. My mother was served on hospice 12 years ago. Her diagnosis was advanced colon cancer for which she sought aggressive experimental treatment. She died six months after diagnosis and was only on hospice a few days. She was 62. Then 2 years ago my grandson was diagnosed with Ewing’s Sarcoma. It’s a very rare soft tissue cancer that generally strikes children (primarily boys) between the ages of 10 and 18. He was nine. After a full year of very aggressive chemo therapy the decision was made to amputate his leg followed by yet another round of chemo, treatment did not work. He died on October 21st 2011 at the age of 11 after being on hospice a few weeks. All three of them died with grace and dignity at home with family by their side. I myself am a two time cancer survivor. Doing this work for more than 25 years, I know how difficult it can be for patients and families to have the tough conversations about their disease, about their treatments and about their dying. I know first-hand what it means to have those conversations and what it means to understand the options and make those life and death decisions. It is never easy, but the more one understands about the options, the better equipped they are to be a part of their own treatment team and the easier it is for their professional care team to collaborate with them in achieving their goals.

Evolution Based on Community Need

Our organization began as a small volunteer program. Like many smaller community organizations across the country, it started with a conversation between a few people who had an idea to improve the quality of life at the end of life. In our case, it was four women who had a vision to create an option for persons in the last few months of life. An option called hospice that would mean people could live and die in their own homes, in familiar surroundings, with family and friends at their side. As our hospice and others around the country were formed and grew, the thing that differentiated hospice from the rest of the health care system was that it truly focused on the whole person (not just their disease) and what they, the patient, wanted. We are guided by a simple question: “What were their goals and dreams for the time remaining?”

In hospice we work at controlling pain and symptoms so that each day can be the best possible for patients and help them reach their goals. The types of goals we hear from our patients can include living long enough to walk their daughter down the aisle on her wedding day, or share their 50th wedding anniversary with their spouse, or see a son graduate from college, or hold that first grandchild. There has occasionally been the dream to get to a Kansas City Chief’s game or take a plane ride, and with donations we’re often able to make those things happen.

But it’s the simple things people usually want. Not the things that money can buy; usually what they want is a little more time and they want it on their terms. It is very common to see patients die soon after reaching their goals. One of the challenges we have in hospice today is the lateness of referrals. Patients and families miss out on the opportunities that could be afforded them with an earlier referral to hospice in terms of understanding their disease and being active participants in decisions related to their terminal condition. In hospice we have learned care is best provided through a team of professionals; individuals with specific expertise who can come together and develop plans of care that will serve the whole patient and compliment what the patient wants. The use of an interdisciplinary team is also the backbone of PACE and an effective way to provide care in all programs, understanding people are more than their disease. Working with the patient’s physician and focusing on the patient at the center of care, we have served all ages and all diagnoses. We’ve grown from serving one county in Kansas to providing hospice care in 15 counties.

In the early days, patients were referred earlier in the trajectory of their disease and were on service longer, many of them for several months. Several years ago, we identified the suffering that occurs from social isolation often accompanying a longer terminal or chronic illness. We began an adult day program at Midland Care Connection to serve that need; a safe place where patients could come and be cared for and socialize with others giving caregivers a respite break and patients an opportunity for interaction with others. Originating especially for hospice patients, it wasn’t long before we had others calling for our help. “My Mom’s got Alzheimer’s” or “Dad’s had a stroke.” They weren’t terminally ill but they needed some help. In fact, typically they are individuals with four or five chronic conditions and often times Alzheimer’s or some type of dementia. Eventually, we saw a decrease in the average

length of stay of our hospice patients, who were too ill to attend adult day care, and an increase in calls needing the help adult day care could offer. And, so our evolution began.

Within 4 years all of our adult day clients were coming from the community at large. They were not our hospice patients. They were adults (18 and older) who had a medical or cognitive frailty that made it unwise or unsafe for them to be at home alone all day. One of the most common diagnoses for those seeking adult day care is Alzheimer's or dementia. The adult day center could meet some basic health care needs, provide new friends in a secure setting for clients, and an opportunity for caregivers to continue working or have much needed respite. The socialization that adult day care provides is one of the most valuable characteristics of the program. Often, those who enroll have been very isolated and the opportunity to interact with others helps them socially, cognitively and ultimately physically as their overall outlook improves. Adult day care really is and has been a bridge for many. It allows individuals to remain in their own homes and avoid premature nursing home placement. The support that adult day provides for caregivers is immeasurable. Not only does it provide education and support with the responsibilities of care giving but it also provides much needed respite for the caregiver allowing time for them. Many of our adult day enrollees have been served in adult day care for as long as 7 years before they were transferred to another service, died, or were institutionalized usually because of increasing dementia care needs.

For Midland, adult day care grew to be more of a community program than an enhancement to hospice services. With that change, we recognized the exhaustion that many caregivers experienced over the course of the many months and years they provided care. That realization led us to begin providing overnight respite care in a small 12 bed residential center. It created a place where a patient could stay when family was called away for business or family emergencies, or just needed to take a break for a few days. It is amazing what a week without caregiving responsibilities can do for a caregiver to rejuvenate and empower them. It is a gift we give when we provide care to someone we love and it is a gift they give to us to allow us to do so, but it can be physically and emotionally exhausting.

At the same time, as our hospice program continued to grow and the needs of our patients became more complex, we added a hospice inpatient facility where we could assist patients struggling with pain or special care needs beyond the family capabilities, or in some cases, where there was no family or friends to give assistance. We also began to encounter more patients who did not fit the 6 months or less requirement of the Medicare Hospice Benefit, but who were experiencing pain and symptoms not manageable by their primary care physician or medical specialist. In response, we developed a palliative care program, providing hospital and clinic consults with some limited home visits. Our physicians, credentialed in hospice and palliative medicine, can intervene with pain and symptom management, but also in assisting patients with the emotional trauma or other aspects of the suffering that often accompanies serious illness. Working with the physicians are nurses, social workers and chaplains with expertise in helping patients at a tremendously difficult time, explaining and educating them about their care, their disease and their choices, and being there to support them in the decisions they make.

Midland Care enrolled our first PACE participants in February 2007. It's a program primarily serving dual eligible individuals, over the age of 55 whom, because of their functional frailty, are eligible for nursing home placement but choose to remain in their own homes. With the help and support of PACE that can be a reality. PACE wraps services around the individual. Through PACE, our team serves both the care provider and the payer for all services. We are at full financial risk for all primary care, acute care, long-term care, supportive care, rehabilitative and maintenance therapies, transportation, adult day care and all personal medical equipment and medications. In short, all the services and care needed. As the 37th PACE program to begin in this country and one of only two in Kansas, we have had the unique opportunity to offer to our community residents a different option from institutionalization. Clients are involved in their care planning based on their goals and working in partnership with the PACE team to achieve those goals. In PACE we have the opportunity for care coordination that is not always available when individuals are piecing their care services together.

Systemic Challenges and Limitations

Unfortunately, PACE is not an option for everyone. Those who have PACE in their area, meet age eligibility, have Medicaid or have income to privately pay can access PACE, but for those younger, most of the middle class and our veterans, this is not an option. As we recognized this fact, we began providing home supportive services like assistance with light housekeeping, errands and personal care and home health services to meet skilled nursing and physical therapy needs. Those services along with adult day care can be integrated and managed to meet most of the care needs. One of the biggest holes in care today is basic case management, which is especially invaluable to our frail elders, those with multiple chronic conditions and those suffering with Alzheimer's. Having multiple providers involved in one individual's care often is challenged with poor communication and incomplete information between providers. We also provide grief counseling for surviving family members. Originally an offering as part of our hospice service, it has now become available for anyone served in any Midland Care program. In reality, grief starts at the time of any major diagnosis. Those families who are involved, educated and supported through the process, though still grieving, will be emotionally healthier as they face their grief at time of loss. For those friends and family members watching the slow deterioration of loved one with Alzheimer's, grief is interwoven into life as recognition and memories fade away. The support and commitment we can give to families through the dying and grieving process becomes a quality of life issue for them as they face a life much changed from what they previously knew.

All of this does not happen easily. There are a plethora of regulations and licensing requirements in every program. There are statutes and standards and surveys. There are billing codes and documentation requirements. Midland Care is licensed by the state of Kansas, Medicare certified and accredited by the Community Health Accreditation Program (CHAP) for hospice and home health. We have an additional home health agency license for home support. We have two licensed adult day centers, a licensed residential care center, maintain a physician clinic for PACE participants and palliative care patients, and have a contract with CMS and the state of Kansas to provide PACE services.

All of this we do with a great deal of commitment to service and quality, with staff who are cross trained to work in multiple programs. We have built a consolidated infrastructure, including central referral and after-hours teams, designed for easy access for patients, efficiency, compliance and an excellent electronic medical record system that functions across all programs.

Our goal is simply that people get the care they need. They don't need to know that it's called home support or that they have to be home bound to access home health or that they have to meet a certain functional level to enroll in PACE or that it's time to call hospice. They just need to call. It's our job to differentiate and comply with the regulations. What people need is the right help at the right time in the right place. Having a variety of programming available to them helps make possible so they're not bounced around to multiple organizations, trying to piece together for themselves what services might help.

The challenges we see in the current care delivery system are the silos that exist throughout not only the health care system but the state and federal regulatory bodies. Currently, in our organization, we undergo about 7 surveys a year. Many times surveyors are looking at the same record on the same patient only in a different program. If we are to effectively serve our communities, not only must we break down silos within our own organizations, we must also display more flexibility at the regulatory level. Utilizing an electronic medical record gives all authorized persons in our organization access to pertinent and real time information on the population we serve. It also cuts down on the redundancy of information patients must give and the time it takes to complete various forms. Even so, we often are spending time completing additional forms and documentation with the same information in different formats to meet regulations. I support the need for regulations and accountability, but most of the regulations we exist under today were developed in another time and without coordinated care in mind. A time when paper was king, triplicate was better and redundancy was expected. Many requirements in programs today are quite antiquated and don't take into account the communication tools and connectivity options we have available to us now. No longer is it necessary for everyone to be physically in the same room to develop effective care plans for patients; it can be done through the internet with electronic medical records and other tools.

As a hospice provider for more than 30 years there are four things that we at Midland Care Connection have learned that are now ingrained into our organizational culture and all the services we provide.

*We've learned that suffering is more than physical pain. As we journey with patients in the last days and months of life often those things with which they may be suffering the most are emotional, spiritual and sometimes even social in nature. Our job is to help identify the source of the suffering and help them where they are. The suffering of a chronic disease over several years, or the knowledge of one's own mind disappearing piece by piece to Alzheimer's disease, or the stark reality of an aggressive cancer all produce suffering that far exceeds the physicality of their disease.

*We've learned today is a gift. Our patients have taught us that each day is to be treasured with the focus on the people we love and not to be wasted on worries and circumstances out of our control. Our role is to add to the quality of life in those days no matter the number, so that patients and families have the opportunity to build memories that will go on.

*We've learned one person has the disease, but the whole family is going through the process. Whether it is someone with a terminal diagnosis with days to live or a new or long-term chronic diagnosis; the patient has the disease but sharing in it with them are those they love and who love them.

*And lastly, we have learned patients and families can get through anything with support. People given clear and honest information and allowed to be active participants in the decisions about their health care are stronger through the process.

Through the years, many patients have accessed multiple services in our continuum but one individual stands out in that he was able to access care in almost every program we offer.

What it Looks like through a Patient Experience

Denzel Ekey was a 78 year old man with Alzheimer's disease and Myasthenia gravis, a disease characterized with generalized weakness in the arms and legs and difficulty speaking and swallowing due to weak neck muscles. He was cared for in his home by his wife Mary. As she explained to me, they had many years earlier completed their advance directives for the sake of their children and for each other. So if the time came that they could not speak for themselves, their wishes could be honored. They first accessed our home support services. Denzel was a gentle giant. A large man both in size and personality, it became too difficult for his wife to provide bathing and personal care, so we arranged for a home health aide to assist with Denzel's showers a few times a week. That continued a few months, along with his attendance at the adult day care center which allowed his wife a break from the constant care-giving responsibilities. At first Mary provided the transportation to and from the day center but as Denzel's condition deteriorated that became more and more difficult. With enrollment into the PACE program we were able to increase services as care needs evolved. With PACE, not only would all of Denzel's primary care needs be taken care of, but we also provided his home support needs and all medical transportation, including daily trips to and from the day center. His decline continued and services were increased accordingly. His wife Mary had some health issues of her own which made it even more difficult to care for Denzel. Mary was hospitalized and required surgery which meant providing care for Denzel would be impossible Denzel was on service for over two years. During that time he utilized just about every service we had available. For the last several months of his life, he lived at our residential center where his wife visited and sat with him daily. When it became evident that his prognosis was not good and with a life expectancy of only a few months, the PACE team initiated end-of-life care, including calling on the hospice team. During the last weeks of his life Denzel

was in the hospice program, arranged for by PACE and living in the residential center. He died on Christmas Day at Midland Care, after having spent the day with his wife at his bedside.

Denzel is not only a wonderful example of the way a continuum of care services can serve someone with advanced illness, but he is also representative of the 13 percent of Americans over the age of 65 with Alzheimer's disease (AD) and 45 percent over the age of 85 who have AD and, the over 200,000 under age 65 with early onset AD. As the fifth leading cause of death for those 65 and older, AD numbers continue to rise. Between 2000 and 2008, deaths attributed to AD increased by 66%, while deaths attributed to the other major diseases of stroke, prostate cancer, breast cancer, heart disease and HIV have decreased. AD is the only cause of death among the top 10 diseases in America without a way to prevent, cure or even slow its progression

It is not just the individual with disease who struggle it is also their caregivers. More than 60% of caregivers rate the emotional stress of caregiving as high or very high, and one third report symptoms of depression. Caregiver health care costs also increase due to the emotional and physical demands of caregiving for a person with this progressive and terminal disease.

All of our patients are very special. Denzel was even more so, because he served on our Midland Care Board of Directors 25 years ago. When we decided to seek Medicare certification for our small not-for-profit volunteer hospice program, he was on the board. When we decided to start adult day care to enhance the care provided in hospice, he was on the board. When we decided to purchase a campus of buildings where we could expand the continuum of services provided to our community, he was on the board. He was a visionary man that saw not just what we were, but what we could be. And we had the honor of serving him with all that we had become. Today his wife continues with our grief support program and has talked of volunteering for us. And that's where we began.

Looking Ahead: Obstacles and Opportunities in Meeting the Needs of an Aging Population

Today there are only 90 PACE programs across the United States. And yet, this is a program that honors what frail elders want, aligns incentives of all the stakeholders and is a predictable budget item to the states. The growth has mostly been stunted because of extensive regulatory and capital requirements. Also, at the state and federal level it is easier and faster to infuse more money into long-term institutional care. In PACE, the provider bears full financial risk for all the health care and long-term care costs of the individuals served and yet many states continue to limit the number of people who can enroll in the program including states like ours who have the 5th highest use of institutional care per capita in the country today. Hospice has grown much faster than PACE but mainly because it's much easier for providers to open a hospice. Even so, of all decedents in this country, roughly 40 percent received hospice and while not all of the others deaths might be appropriate for hospice care, a significant portion are or would be.

Clearly there is an evolution, if not a revolution, in health care today. Partly driven by budgetary and resource allocations, but much of it being driven by a generation that has been making its mark since the

end of World War II. Those baby boomers who advocated for change in the 60's are still advocating for change today. And change will surely have to come because of the sheer volume of individuals who will need care and the disproportionate number of caregivers available to provide the care both familial and professional. The number of Americans surviving into their 80's and 90's and beyond is expected to grow dramatically due to advances in medicine and medical technology, as well as social and environmental conditions. By 2025 the number of people with AD will be 6.7 million, a 30% increase from the 5.2 million currently affected.

We have in this country two programs that have developed around what people desired for their health care - hospice and PACE. Both programs born out of grassroots efforts have been placing the patient at the center of care for 40 years. Both developed to serve patients in their place of residence, honoring choices and the right to be involved in their own health care decisions. Both serve holistically utilizing a team, understanding patients are much more than their disease process. Both have been empowering patients and those who loved them to be educated on options and involved in the process of their health care delivery. Both have been shown to decrease emergency room visits and hospitalizations not only because of the comprehensive nature of the service they provide but because they're available twenty-four hours a day, seven days a week, making the home visits, providing the needed care at the bedside and calming fears. There is much discussion out today about new and innovative ways to deliver health care. In reality we have two of the best examples already in our midst and yet both continue to be underutilized.

I would like to provide a framework for developing a health care delivery system that works well for patients with advanced illness. Patients with advanced illness need access to care models with the following features:

- **Provider-based:** as illness advances, the direct link between those who provide care to an individual and those responsible for coordinating and planning care becomes especially important. In hospice, our programs are not only paying for care, or managing care, they are also providing care. Through hospice services, providers and patients work together to identify health care needs, develop care plans, and implement those care plans. This closely-knit community embodies a patient-centered approach and facilitates patient/provider relationships that ensure coordination, quality, and personal satisfaction.
- **Interdisciplinary Teams (IDT):** Hospice programs use an interdisciplinary team (IDT) that includes doctors, nurses, therapists, social workers, dieticians, personal care aides, and others who are directly responsible for the day-to-day care of our participants. This daily interaction between the team's members and the individual receiving care, and between the team's members themselves, allows for ongoing and timely patient and caregiver education, advanced care planning, and care coordination.

- Caregiver support: Caregivers are an integral part of quality care for individuals with complex and advanced illness. The hospice model strives to support caregivers by including them in the care planning process, discussing care planning such as advanced directives, and providing respite and family support.
- Financing and accountability: Hospice programs receive capitated payments that provide incentives to ensure high-quality care. The financing model bundles fixed payments from Medicare and Medicaid or private sources into one flat-rate payment to provide the entire range of services a person needs. As a result, hospice is accountable to its enrollees and their families while accepting full responsibility for the cost AND quality of care provided.

Each of these characteristics contributes to the high quality of care that hospice programs provide to individuals as they address advanced illness. I would add that my conviction that these are essential attributes of quality care for people with high care needs has been affirmed by my experience as a PACE provider. PACE programs serve a population similar to hospice, reaching the people they serve when they are at a nursing home level of care. These programs share hospice's provider-based model, its effective use of interdisciplinary teams, strong caregiver support and financial accountability. As our country seeks better care for people with advanced illness, hospice and PACE are leading the way as effective care and financing models.

I encourage the Committee and Congress to take what is working within the existing system, namely and hospice and PACE, and use these programs as the model for how to improve on the larger health care continuum. More patients, if not all patients, with advanced illness should have access to this type of seamless, coordinated and patient-focused care. And, they should have access to it earlier.

I want to thank Chairman Kohl, Ranking Member Corker, Senator Whitehouse, my own Senator Moran, and the Committee for allowing me to testify. With me and with Midland Care, you have a willing partner in expanding high quality care across the health care system.

**United States Senate,
Special Committee on Aging**

June 13, 2012

**Testimony of Albert Gutierrez, President and CEO
Saint Joseph Regional Medical Center,
A Ministry Organization of Trinity Health, Novi, Michigan**

Prescriptions for Hope

Introduction

Distinguished members of the Senate committee, colleagues in health care and members of the public, I am honored today to give testimony, on behalf of Saint Joseph Regional Medical Center, on the issues related to improving health care for individuals with advanced illness.

We all know that navigating our health care system is not easy. It becomes even more complex when a loved one has an advanced illness, particularly an illness that brings the end of life.

I will attempt to take a very complex issue about which volumes have been written and consolidate it into my allocated time today.

For the purposes of these proceedings, there are several structural elements related to empowering patients and honoring individual decisions in care.

A Prescription of Hope for Suffering

Part of the wide variation in treatment modalities for suffering, and its related expressions, is the wide variability in individual tolerance to suffering – the tolerance of the patient, but also the tolerance of the loved ones who are watching the person suffer. Suffering occurs when one is deprived of clinical and emotional support. When we observe suffering in another human being, God gives us all the remarkably reflexive response to preserve life. I'm sure the committee has witnessed this behavior in the selfless heroism of our soldiers on the battlefield and the individuals who rushed to help those who were injured or afraid at Ground Zero, among innumerable other examples. This instinct to help a fellow human being is remarkable.

Countless times every day in health care facilities around our country, this natural instinct to help and heal arises in the compassionate caregivers who receive the suffering at their doors. Unfortunately, in pursuit of a noble goal – relief of suffering – we frequently offer ineffective, costly and painful procedures. But, this does not have to be the way. We actually know what patients want in advanced illness. They want us to minimize their pain, reduce the burden on their families and to give them some control over what is happening. These patients

also want to avoid prolonging the dying process, and they want to strengthen relationships with their loved ones.

Sounds simple, doesn't it? This is where faith can make a big difference. My hospital, Saint Joseph Regional Medical Center, is part of Trinity Health, a Catholic health care system working to alleviate suffering across communities in ten states. Caring for the body, mind and spirit of every person we touch is core to our Mission, and embedded in the words of our Mission statement. One way we are living this out is through an initiative to promulgate palliative care programs across our health system during the next year.

As a ministry of the Catholic Church we believe every human life is worth living. Palliative care reflects our commitment to respecting the dignity of every human person. We believe palliative care to be a prescription of hope for suffering.

A Prescription of Hope for Society

Good medicine is ethical medicine and good medicine yields high quality, cost-effective outcomes. Palliative care, including hospice care, allows us to deliver good medicine. Very simply stated, palliative care is patient- and family-centered care that optimizes quality of life by anticipating, preventing and treating suffering. What is truly amazing about palliative care is that, while it alleviates suffering for the patient and family, it improves the quality of the care and reduces costs.

Here are some sobering statistics to consider: The average number of physician visits required by patients in the last six months of life is 34.8 – in other words, these patients need to see the doctor almost six times a month (Premier Health ACO Readiness Assessment, 2011). There are better ways for one at the end of life to spend their time.

We know that extensive use of health care resources does not enhance the quality of life at the end of these precious lifetimes. In fact, research shows that in the final week of life, “less really is more.” High scores on measures that assess the quality of death are most closely correlated with lower per capita cost (Zhang, B. et al. Arch Intern Med 2009; 169: 480-488).

Patients should know they have a choice – they have a right to forgo costly, burdensome, extraordinary or disproportionate interventions that merely extend the length of life with no reasonable hope of real benefit. Palliative care is higher quality care with better outcomes. Why? Because palliative care clarifies goals

with patients and families. Palliative care helps families select the appropriate medical treatments and care settings that best meet these goals. And, palliative care helps patients navigate a very complex health care system.

At Saint Joseph Regional Medical Center, we help families with those hard decisions about if, or when, to withhold death-prolonging treatments, while respecting the sanctity of life and not accelerating the process of dying.

In order for a patient to make sound decisions within those parameters, they must be engaged in conversation. Herein lies the hope that we as a society can ensure these conversations are happening. As Catholics, we call this being “good stewards of our resources.” We need to use deep discernment to provide the right resources at the right time.

A Prescription for Hope for Each Precious Life

At the core of our prescription for hope is establishing the vital conversation between individuals, their loved ones, and their care providers – a conversation that is currently not occurring enough across our country. Failure to decide on advanced directives, and make their individual wishes known to their family members ahead of a crisis, leaves people left to face those critical decisions in the midst of highly charged physical and emotional circumstances. It is all of our responsibility, distinguished members of the Senate, to empower our citizens to make informed decisions about advanced illness and end-of-life care.

Let me share a story with you. I challenge you to listen closely to identify the threads of hope embedded within this true story. It demonstrates the issues that can arise when we don't have those crucial discussions before a time of serious illness. It also demonstrates how we, at Saint Joseph Regional Medical Center, rose to the occasion to do our best despite difficult circumstances.

A 60-year-old man who had suffered a massive stroke showed up alone at our emergency room. After appropriate CAT scans and other examinations, the doctors agreed that the damage was so great he would not recover. Someone called the only number on his cell phone list, his boss, who said the man had no known family. Our Saint Joseph Regional Medical Center legal staff exerted every effort to locate his next of kin, even getting permission to search his apartment for an address book, all to no avail. The doctors had determined that the curative line of care was not possible, and his boss was not willing to take the responsibility of serving as his guardian. We convened an ethics conference and, based upon our

recommendation, the judge appointed a guardian. After extensive discussions with the doctors and a clear understanding of the medical facts, the assigned guardian decided that the best interest of the patient was to remove the hopeless extraordinary interventions and move him to hospice care. She visited him regularly to ensure that he was always clean and comfortable before he died 10 days later. Because he had identified himself as an organ donor on his state identification card, we were able to use some of his tissue to help others in their healing process. Saint Joseph Regional Medical Center paid his funeral expenses, and he was buried in a local cemetery.

So, did you see the hope in that end-of-life story? The patient died with dignity, with his desire to be an organ donor fulfilled. Embedded there, too, is the message of hope for each precious life. With more attention and tools, we can have the blessing of a better end bestowed upon each of us.

Closing Recommendations

I want to leave you with some concrete recommendations based on our experience at Saint Joseph Regional Medical Center. As a Catholic institution, we are committed to caring for every person who comes through our doors, and to making sure that commitment sustainable. We have long encouraged the kind of conversations that I described as prescriptions for hope, and we are making deliberate choices to help that happen more consistently. Here's what I urge you to include in our nation's health care policy:

First, we need to ensure that palliative care programs and providers are in place across our country. Holding true to our Catholic values, Trinity Health is doing its part and advancing an initiative over the next year to assure that a palliative care program is present in all of its hospitals. Programs like ours help patients, especially seniors, navigate the very complex health care system. They also will provide trained professionals who can assist our seniors, our patients with advanced illness, and all their families with critical "what if" conversations when they need it most – when they are healthy.

Second, we need to shine light onto end-of-life care as a societal issue to be addressed. No longer should it remain in the shadows. Faith-based organizations such as ours stand ready and willing to initiate this national conversation. Americans have widely divergent views on dying, death and life after death, and many of our fellow citizens prefer not to face the issues at all. Too long has our country shied away from these tough conversations,

and our inability to deal with it is causing our citizens to suffer physically, emotionally and economically. The time for this is well past.

Third, we need to establish the guarantee that no one dies alone. Just as we saw with the end-of-life care given to the stranger who came to our door – including the expert involvement of hospice – we are committed to providing comfort and dignity to every person. But no one should have to face the end of life alone. I believe part of the instinct that I talked about – to help the sufferer – means that even when our efforts fail, even when we cannot save or heal, our human solidarity means that we do not abandon them in those last moments. The comfort of that hope, that recognition of the common good, can free us all to make the choices that are best for each of us, our community and our nation.

About Saint Joseph Regional Medical Center

Saint Joseph Regional Medical Center is a not-for-profit, multi-hospital health system located in North Central Indiana.

Our system includes:

- 254-bed acute care hospital at the Mishawaka Campus
- 58-bed acute care hospital at the Plymouth Campus
- 40-bed Saint Joseph Rehabilitation Institute
- 20 practices of the Saint Joseph Physician Network
- Community health centers and additional points of access

The first institution in South Bend to care for the sick, Saint Joseph's Hospital was established in 1882 by the Sisters of the Holy Cross. Today, SJRMC is a Ministry Organization of Trinity Health. We provide personalized, faith-based care paired with the latest in advanced medical technology and procedures.

We are proud to provide private rooms at all of our hospitals, as we strive to create a healing environment and deliver excellence in the patient care experience. In addition, thanks to tremendous support from our communities and the fundraising efforts of our Foundation, our community health centers and outreach programs provide critical medical services for the uninsured and underinsured members of our population.

At SJRMC, our values give us strength. That character guides every decision we make - even when those decisions are complicated, costly, or hard. We honor our mission to heal body, mind and spirit by investing in technology, people and capabilities that allow us to set the standard for quality care. Because we answer to a higher calling.

For more information about SJRMC, visit www.sjmed.com

About Trinity Health

Trinity Health is among the largest Catholic health care systems in the country. Based in Novi, Mich., Trinity Health operates 49 acute-care hospitals, 432 outpatient facilities, 33 long-term care facilities, and numerous home health offices and hospice programs in 10 states. Employing about 56,000 full-time staff, Trinity Health reports about \$9.0 billion in unrestricted revenue. As a not-for-profit health system, Trinity Health reinvests its profits back into the community through programs to serve the poor and uninsured, manage chronic conditions like diabetes, health education and promotion initiatives, and outreach for the elderly. In fiscal 2011, this included more than \$453 million in such community benefits. For more information about Trinity Health, visit www.trinity-health.org, follow @TrinityHealthMI on Twitter, or become a fan of the Trinity Health Facebook page at www.facebook.com/trinityhealth

TIME

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The Long Goodbye

By Joe Klein



The phone call came on a cloudy morning in Iowa. I was interviewing Senator Chuck Grassley in his farm kitchen, surrounded by a sea of corn. Mom was back in the hospital again. She had pneumonia. She wasn't eating. "If we don't put in a feeding tube," my mother's internist told me, "she won't survive on her own."

Mom had always been vehement about how she wanted to go. "Just pull the plug. Let me die," she would say, with more than a hint of melodrama. "I don't want to be a vegetable." But was she a vegetable now? She had been suffering from dementia for several years and at times seemed to be living on a different, prohibitively weird planet populated by angels, murderers and secret paramours. At one point, I called from the road, and she told me she had taken a lover. He was in bed with her right now. They had made love three times. (She was 91.) "Where's Dad?" I asked. In the other room, she said. Which was true, both literally and metaphorically: Dad was also suffering from dementia but of a less florid and more truculent variety. He rattled between wild rages and utter forgetfulness; he was intermittently incoherent, having lost much of his ability to locate words.

Over time, though, Mom's angels and imaginary lovers disappeared, and an eerie dullness set in. She was rather limited in her responses now. "That's nice," she would say when I told

her about my children and grandchildren. "I love you too," she would say. She never initiated conversation, but occasionally I could still make her laugh. Vegetables don't laugh.

"If we don't put in the tube, how long does she have?" I asked the doctor. He wasn't sure. He was the sort of doctor who was allergic to certainty or even to ballpark estimates. "We've taken care of the pneumonia, but she's not eating," he repeated. So weeks? Days? She needs nourishment, he said. I was in Iowa. My brother was in Asia. I didn't want to sign a death sentence without even seeing her, without giving her a chance to rally. "O.K.," I told the doctor. "Put in the feeding tube. I'll be there as soon as I can."

That was the beginning. I spent the next five months as a death panel for both my mother and my father. They passed away within a few weeks of each other last winter. The circumstances of their deaths were not unusual; many of my friends have been through similar experiences with their parents in recent years. But we grieve in different ways, and my way, I guess, is to write about it--and also to examine the policy implications of how we treat the elderly. Because it is clear to me, after this awful winter, that there are better ways to handle the endgame. I now believe, for example, that I made a mistake when I agreed to Mom's feeding tube. I believe that because I was extremely fortunate to transfer my parents, at the end, from regular fee-for-service Medicare to a private nursing home that used the Geisinger health care system, in which--as with the Mayo Clinic and others--doctors are paid salaries and outcomes-based performance bonuses rather than by the services they perform. It is a system that many health care experts see as a model, a way to save significant amounts of money while providing better care. I can't personally attest to the savings--although, as we'll see, the statistics are impressive--but I can say that the level of candor, sanity and humanity of the Geisinger doctors I dealt with was stunningly high. They helped me through some of the toughest decisions I've ever had to make. My parents died serenely, with dignity. When you are a death panel--when the time and manner of their passing is at least partly in your hands--that is the very best you can hope for.

But humanity before policy: let me tell you a little bit about my parents. They were born within a month of each other in 1920. They met on the first day of kindergarten. At P.S. 114 in Rockaway Beach, Queens, the children were arranged by height and marched into class together in two lines. My father was the shortest boy, my mother the shortest girl. They walked into class that first day holding hands. It wasn't exactly a straight line ever after. Rummaging through their memorabilia, I found a picture of Ensign Malcolm Klein with a date at the Coconut Grove in Boston during the months that the U.S. Navy had sent him to

Harvard Business School for advanced training as a supply officer in 1942. I found pictures of Mom with other guys as well. But Mom and Dad became engaged during the war, were married on May 13, 1945, and were inseparable after that.

Dad grew up in an upper-middle-class family; Mom was poor. Dad's father kept the books for the John F. Curry insurance agency--which meant, in effect, that he kept the books for Tammany Hall. Curry was boss during the Roaring '20s, the Jimmy Walker era. The '20s also roared for my mother's father Frank Warshauer. He was a professional musician who wrote a couple of Top 40 hits, which enabled him to buy a two-family house on the less fashionable bay side of Rockaway. (Dad's home overlooked the ocean.) The Warshauer house was my first home. If you've seen Woody Allen's film *Radio Days*, which takes place in Rockaway Beach, you get the picture: my parents and I lived upstairs; my grandparents and two maiden aunts, Rose and Madeline, lived downstairs. The aunts eventually become part of the family retinue when my grandparents passed away.

Dad's ability to provide for everyone began with an incredible piece of luck in 1942: he won the largest daily double in the history of the Suffolk Downs race track: \$1,877.40. "Ensign Klien [sic] says he will use his winnings to purchase war bonds," the *Boston Record* reported. After the war, he used the money to buy a small printing company. By the time I joined the payroll at the age of 14, the company had grown to nearly 100 employees and was doing some of the finest lithography in New York.

I was extremely proud of my dad. I could see how his employees respected him. But they feared him too, and so did I. He had made an implicit deal with my mom: she was allowed to have her sisters live with us, and he was allowed to go about screaming like a banshee. He and Mom had a loving marriage, and they had fun. I have in my possession a certificate from the Irv Siegel School of Social Dancing honoring Mal and Miriam Klein for proficiency in "mambo, cha-cha-cha and merengue." But Dad was a terrifying presence in our lives. Even his fatherly duties--helping with a Cub Scout project or coaching Little League--were occasions for embarrassing rages. I mention this because his anger intensified as he began to lose his wits; it was the terrain on which I had to maneuver as I sought to make decisions regarding my parents' health and safety after they retired to State College, Pa.

Dad bought a lovely house in Brookline Village, one of those progressive-care communities that enable you to slide toward senescence from the complete independence of a single-family home to assisted living to nursing care, although Dad refused to slide. He remained

flagrantly, stubbornly independent, running his household, which included my two inevitable aunts, even as his health began to decline and then plummet. All four were cared for during the day by two lovely Kazakh women whom Dad hired independently of Brookline Village, but as the years passed, it became apparent they weren't enough. Mom had gone blind--the victim of a rare form of glaucoma that wasn't detected until it was too late--and she suffered from neuropathy, which weakened her legs. Both she and Rose would fall on the way to the bathroom at night; the home health aides would find them on the floor in the morning. My brother and I suggested that he expand the home health care to a 24/7 operation--the Kazakhs had friends who would take the night shift--but Dad refused. "If he ran a nursing home with these conditions," my brother said, "he'd be arrested." (Dad relented only after a hospice worker, who would come to care for Aunt Rose as she neared death from congestive heart failure, threatened to call the authorities and have Mom and Rose removed.)

Things became impossible. Dad was going blind too, but he refused to give up his driver's license. I had to call the police to have it taken away, but he continued to drive anyway. At one point, his urologist called to tell me that Dad had driven into his parking lot and knocked down a sign: "Do you really think he should be driving?" After that, I had the Kazakhs hide the car keys. Dad followed Mom's precise path downward: his macular degeneration grew worse, he developed neuropathy, and dementia set in. He gave orders to his bookkeeper--who was now trying to keep track of the money owed six Kazakh caregivers--and his investment adviser, forgot them and then screamed. He fired the bookkeeper; the investment adviser quit. He caused a public ruckus by claiming that the manager of Brookline Village was cheating the homeowners, which made it impossible, initially, to move Rose and Madeline into either the assisted-living or nursing-home facilities there. He became credulously obsessed with his junk mail, sending thousands of dollars in donations to "charitable" lotteries run by phony patriotic and veterans groups. I'd tell him he was wasting his money, and he'd say, "But look at the printing. It's a beautiful four-color job." He screamed at the Kazakhs, who were patient beyond imagining. He screamed at Mom when the angels and murderers hovered about; he was a bit daunted by her phantom lover though.

Rose passed away in December 2010, and Mom began to decline thereafter. The emergency runs to the hospital became more frequent. She broke her elbow, her hip. And then, finally, came the pneumonia, and the feeding tube in October 2011. By this time, I'd had private conversations with several of my parents' doctors, who agreed--informally--to allow me to

exercise my medical power of attorney. (My son, a lawyer, held the financial power of attorney.) We couldn't do this formally because Dad would have taken me to court. He was infuriated with me for stopping him from driving and forcing him to have full-time home health care. The hazy legality of the situation was exacerbated by the nature of the Medicare system. There was no coordination among the flotilla of physicians taking care of my parents. There was no real supervision of their daily drug taking: Dad was in charge, and sometimes he'd screw up; it was hard for me to communicate on the phone with the Kazakhs, whose English was spotty. On several occasions, Mom was rushed to the hospital because the drugs prescribed by her various doctors had interacted poorly or Dad had given her the wrong dosage. Their internist was a sweet man, but he refused to confront my father. My brother, who was living in Asia by then, figured that only a disaster would change the situation. Instead of a disaster, though, we lucked into Geisinger.

Happily, the manager at Brookline Village was willing to forgive Dad their very public battle and let me move them into the on-site nursing home, called the Fairways. I told Dad it was necessary for Mom to go there because of the intricacies of the feeding tube, which wasn't entirely true. And then I reminded him, "You always said you wanted to be with her. Maybe you should go in too. It'll help Mom recover." He agreed, then forgot we'd had the conversation. It took three more such talks--one with their internist--to get him into the facility, and even then, Dad would try to break out. He occupied the elevator in protest one day; I had the nurses give him a tranquilizer. And I must admit, I could see his point. The nursing home was first-rate, with a wonderful staff, but it was a death factory. People went in and didn't come out. The fellow in the room next to Dad's, a stroke victim, roared and cried incomprehensibly throughout the day, a terrible sound. "Why can't we just die at home?" Dad asked. It was a fair point, but I couldn't give the real answer: because it was safer for them in the nursing home and, as I soon learned, the quality of medical care--which was provided by the Geisinger system--was much better than what they'd been receiving.

My first conversation with a Geisinger doctor, Victoria Devan, was refreshingly different in a no-bull sort of way. I told her I had mixed feelings about Mom's feeding tube, that Mom had left clear instructions against prolonging her life--but I'd been out of town, I'd wanted to see if she would recover her appetite, and I wasn't sure how many days she'd have if we didn't put in the tube. Devan said she understood, "but we should keep a close eye on it. When they lose their appetites, they're usually telling us something." Devan also told me that Mom would have had weeks, perhaps a month, more of life if we hadn't inserted the tube. What a

relief: clear, simple sentences. When I asked Devan about it later, she said she'd been relieved as well. "You got it," she said. "Sometimes the family members don't. Sometimes they want us to do all sorts of things that just aren't realistic, and we have to be very patient about walking them through the reality of the situation. You understood where it was heading."

A week later, I checked in again with Devan. Mom was eating less than 10% of her meals. "Maybe we could reduce the amount of food she's getting through the tube and see if her appetite revives?" I asked. Devan agreed but told me once again, gently, that the odds were that Mom wasn't coming back. And she was right. After another week had passed, my brother came home from Asia, and my wife and children joined me in State College for a meeting with Dr. Charles Maxin, who was Devan's senior colleague. He seemed like a figment of Norman Rockwell's imagination--calm and reassuring and flagrantly decent. Like Devan, he didn't mince words. Mom wasn't responding; we were only prolonging the inevitable. He told us her death would not be painful. I looked around at my family and asked if anyone had any objections to pulling the plug on Mom. No one did.

"There's one other thing," Maxin said. "I noticed that your mom has a do-not-resuscitate order in her file, but your dad doesn't. Should we add it on?" I told Maxin that Dad acted as if old age were a reversible condition. He probably would want to be resuscitated. "Are you sure about that?" he asked. "You know that he broke two ribs when he fell in the bathroom last week. He's very frail. If we tried to resuscitate him, we'd probably break the rest of his ribs." This was startling but undeniable. I approved a do-not-resuscitate order for Dad. It was becoming clear to me that in the gentlest possible way, these Geisinger doctors did not mess around.

The Geisinger medical center seems almost like a mirage. It is a giant, state-of-the-art medical facility plopped down amid farmland in the town of Danville, Pa. The hospital is the mother ship of an extensive network of medical practitioners tending to 2.6 million patients in 44 mostly rural Pennsylvania counties, including the doctors who took care of my parents at the Fairways. It was founded in 1915 by a widow named Abigail Geisinger and first directed by Harold Foss, a surgeon who had been an assistant to the famed Mayo brothers. Like the Mayo Clinic, it employed a team approach, with doctors, paid as employees rather than as independent operators, cooperating on patient care. "It's like hiring a general contractor to supervise the renovation of your house," says Henry J. Aaron, a health expert at the Brookings Institution. "He brings his team of subcontractors and coordinates their

work. It's a lot more efficient than finding and organizing the carpenters, the electricians and the painters by yourself."

There are good contractors and bad ones. The accountable-care-organization model--which is the emerging term of art for places like Mayo and Geisinger--was emulated in all its worst aspects when health-maintenance organizations (HMOs) emerged as a cost-cutting tool in the 1970s and then became unpopular when they became synonymous with hellish bureaucratic medical rationing. But during the years that HMOs were going in and out of fashion, a quiet revolution was beginning--the computerization of medical records. And Geisinger became a pioneer in analyzing those records to find out which sorts of treatment worked and which didn't. Over time, as the data accumulated, it has become clear that quality health care can be provided in a way that makes patients happy, with a minimum of draconian bureaucracy and for less money. "Our core belief is that about 40% of what doctors and hospitals do is wasteful," says Dr. Glenn Steele, Geisinger's president. "If you can extract that percentage of crap, you can redistribute it into savings and profits but also into procedures that actually help patients."

Geisinger has found, for example, that by adding case managers--nurses who work by phone and in person from doctors' offices--to chronic elderly-care cases (like my parents before they entered the nursing home), they can give more individual attention and produce better results. The case managers call or visit the patients regularly to make sure they've taken their medication, weighed themselves (on Bluetooth scales that send the results to the Geisinger computers), are eating the right things and are aware of upcoming appointments. They are also there to listen to complaints, which, as those of us who've been through parent care know, are not infrequent. A study published in the *American Journal of Medical Quality* found that this system produced 18% fewer hospital visits, a staggering 36% fewer return visits and cost savings of 7%. "Geisinger has made steady progress in reducing per capita Medicare costs over the past 20 years," says Dr. Elliott Fisher of the famed Dartmouth Institute for Health Policy and Clinical Practice. "It has gone from the middle of the pack to very near the top."

Over those years, Geisinger has quantified almost every aspect of health care. A bundle of nine routine procedures has been identified to treat diabetics, for example. The bonuses that Geisinger doctors receive depend on how closely they adhere to proven procedures, as monitored by the Geisinger computers. Bonuses also depend, in part, on how the patients rate their care, and doctors--who are not always the most sociable human beings--are asked

to go through a bedside-manner orientation program called Patients 101, which schools them in basic procedures like shaking hands with members of the patient's family, looking them in the eye and introducing themselves. This sort of training is especially important in a system in which doctors sometimes must try to deny care requested by patients or their families that is deemed unnecessary. "It takes more time and effort to sit down and have a discussion with the patient rather than just ordering the duplicative X-ray," says Dr. John Bulger, Geisinger's assistant chief quality officer. But the time spent on the discreet application of candor saves money and develops a deeper level of patient trust and satisfaction.

In my parents' case, Geisinger had worked with the nursing staff at the Fairways. I was consulted about every adjustment in medication and told about every time Dad tried to do a walkabout and inevitably fell down. By the third week, the staff and I were co-conspirators, laughing about Dad's stubbornness and trying out new strategies to make him more content. The situation was, of course, horrific--Mom and Dad were both fading away--but I no longer felt so guilty and frustrated. I was part of a team making their passage as comfortable as possible. After the struggles I'd been through with Dad, it's hard for me to describe what a relief this was.

"This is such a terrific model," says Henry Aaron. "It costs less and gives better results. In a Darwinian business system, you have to wonder why it doesn't spread." Only about 33% of Americans get their health care through organizations like Geisinger. But the model is becoming more popular, encouraged by the Centers for Medicare and Medicaid Services (CMS), which has run hundreds of pilot projects over the past six years. "If you're a group practice that joins one of the CMS pilots and prove you can improve service while cutting Medicare costs, you get to keep a portion of the savings," says Fisher. Much of the savings projected for the Affordable Care Act--Obamacare--would come from a broader application of his model.

But that's going to be a big fight and difficult to win: most doctors don't like the Mayo-Geisinger way of doing business. The culture of fee-for-service medicine, which features each doctor as the captain of his or her own ship, is incredibly powerful. "What you hear from doctors who don't like our system," says Steele, "is 'We don't want to be robots run by your computers.' But we encourage innovation if it really works." Devan says that while Geisinger doctors don't have to worry about the business hassles of running a fee-for-service practice, it isn't exactly natural for doctors to have their work under constant scrutiny by

their peers. "We have monthly meetings where each patient is reviewed," she tells me. "That's a major cultural shift for most doctors."

The shortcomings of fee-for-service medicine are well known, especially when it comes to Medicare. At the age of 80, my mother insisted on having a heart-valve operation to fix a murmur she'd had since birth. "It's getting worse," she said. "I'm feeling more tired than I used to." The going rate for such operations was more than \$100,000, and Medicare paid for hers. The current system is rife with such unnecessary expenditures--"We're having a national epidemic of wrong patient operations," Fisher says--and it seems clear that a model like Geisinger's, in which doctors aren't rewarded for performing extraneous tests and operations, would be the best way to reduce the costs of Medicare. It also seems clear that asking people like my parents to make market decisions about their health care--the sort of system that Congressman Paul Ryan and other Republicans support--would be an act of cruelty and an unnecessary one at that. In the end, changing the way health care is provided rather than the way it is sold may be the most efficient way to generate savings.

Doctors are trained to do whatever they can to save a patient, even an elderly one, and that is an excellent thing. But that Hippocratic impulse has been subtly undermined by the rewards of fee-for-service medicine and by the threat of malpractice suits, which militate in favor of ordering the extra MRI or blood test or dialysis even for a patient who probably has only weeks to live. And so it was that when my father was rushed to the Mount Nittany Medical Center suffering from acute kidney failure in late January, the immediate impulse of the doctors in the emergency room was to try to revive him by rehydrating him. "That's how they're trained," my father's urologist, Dr. Charles Dalton, told me. Dalton is a terrific fee-for-service doctor who had impressed me with his Geisinger-like candor in the past. "But [rehydrating him] was probably the wrong thing to do," Dalton went on. "Renal failure is a good way to go. You just go to sleep. Your dad's kidneys are pretty much shot. You may revive him, but he'll be back here in a month, six weeks."

My next decision seemed obvious, but it was much tougher than removing Mom's feeding tube. This was Dad. He had always haunted my dreams, and now I had visions of the Mighty Malcolm rising from his hospital bed, screaming at me for trying to kill him. But that Malcolm had disappeared after Mom passed away in November, a few weeks after the meeting with Maxin. At the end, I had fed her several teaspoons of chocolate ice cream and said, "I love you, Mom." Her last words were "I love you too." An hour later she was gone.

The next morning, I told Dad that for the first time in 86 years, there was no Miriam. "Is it definite?" he asked, crushed. His will to live vanished. He pretty much stopped eating. I tried to revive his interest in food by having the nursing home serve him more of the things he loved to eat--salads, pancakes, a glass of sweet white wine with dinner. "You did that? That's amazing," he said of the wine. "I really appreciate what you're doing. You're a good son," he said for the first time in my life. I told him he had been a great dad. "I could have been better," he replied.

But he forgot to ask for the wine with dinner. And he often forgot to eat dinner. He slept through most days. And about eight weeks after Mom died, his kidneys failed and I faced a final decision. Anil Aleti was the Geisinger doctor on call at Mount Nittany, and he was every bit as forthright as Maxin and Devan. We could keep Dad going with intravenous hydration, and he might last a month--there was no question of inserting a feeding tube--or we could stop. I called my brother and told him that I'd decided to let Dad go. He agreed, as he had every step of the way.

I sat by Dad's bedside for that final week in the nursing home. He opened his eyes a few times and tried to speak, but he couldn't. I held his hand; he squeezed mine once or twice. The morning he died, two angels from hospice care sat with my wife and me by his bedside; the nursing staff and Dr. Devan hovered about as well. Betsy Brett--the hospice supervisor who had been on the case since Rose died and had seen Dad rage against his twilight--explained how it would be. His breathing would become shallower, then more intermittent, then stop. And so it went: Dad seemed to sigh at the end. He inhaled and sighed and was gone. He was not a religious man, but there was a gorgeous serenity in this moment--and there was a certain satisfaction for me too, surrounded by the caregivers who had helped me through this passage toward my own maturity, caregivers who really knew how to give care.

TO WATCH JOE KLEIN TALK ABOUT HIS STORY, GO TO time.com/klein_video

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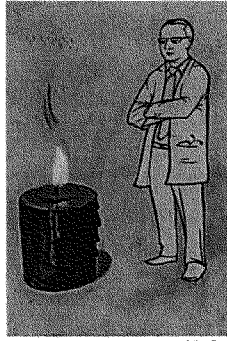
LIFE & CULTURE February 25, 2012

Why Doctors Die Differently

Careers in medicine have taught them the limits of treatment and the need to plan for the end

By KEN MURRAY

Years ago, Charlie, a highly respected orthopedist and a mentor of mine, found a lump in his stomach. It was diagnosed as pancreatic cancer by one of the best surgeons in the country, who had developed a procedure that could triple a patient's five-year-survival odds—from 5% to 15%—albeit with a poor quality of life.



What's unusual about doctors is not how much treatment they get compared with most Americans, but how little.

Art by David

Charlie, 68 years old, was uninterested. He went home the next day, closed his practice and never set foot in a hospital again. He focused on spending time with his family. Several months later, he died at home. He got no chemotherapy, radiation or surgical treatment. Medicare didn't spend much on him.

It's not something that we like to talk about, but doctors die, too. What's unusual about them is not how much treatment they get compared with most Americans, but how little. They know exactly what is going to happen, they know the choices, and they generally have access to any sort of medical care that they could want. But they tend to go serenely and gently.

Doctors don't want to die any more than anyone else does. But they usually have talked about the limits of modern medicine with their families. They want to make sure that, when the time comes, no heroic measures are taken. During their last moments, they know, for instance, that they don't want someone breaking their ribs by performing cardiopulmonary resuscitation (which is what happens when CPR is done right).

In a 2003 article, Joseph J. Gallo and others looked at what physicians want when it comes to end-of-life decisions. In a survey of 765 doctors, they found that 64% had created an advanced directive—specifying what steps should and should not be taken to save their lives should they become incapacitated. That compares to only about 20% for the general public. (As one might expect, older doctors are more likely than younger doctors to have made “arrangements,” as shown in a study by Paula Lester and others.)

Why such a large gap between the decisions of doctors and patients? The case of CPR is instructive. A study by Susan Diem and others of how CPR is portrayed on TV found that it was successful in 75% of the cases and that 67% of the TV patients went home. In reality, a 2010 study of more than 95,000 cases of CPR found that only 8% of patients survived for more than one month. Of these, only about 3% could lead a mostly normal life.

Unlike previous eras, when doctors simply did what they thought was best, our system is now based on what patients choose. Physicians really try to honor their patients' wishes, but when patients ask “What would you do?,” we often avoid answering. We don't want to impose our views on the vulnerable.

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The result is that more people receive futile “lifesaving” care, and fewer people die at home than did, say, 60 years ago. Nursing professor Karen Kehl, in an article called “Moving Toward Peace: An Analysis of the Concept of a Good Death,” ranked the attributes of a graceful death, among them: being comfortable and in control, having a sense of closure, making the most of relationships and having family involved in care. Hospitals today provide few of these qualities.

Written directives can give patients far more control over how their lives end. But while most of us accept that taxes are inescapable, death is a much harder pill to swallow, which keeps the vast majority of Americans from making proper arrangements.

It doesn't have to be that way. Several years ago, at age 60, my older cousin Torch (born at home by the light of a flashlight, or torch) had a seizure. It turned out to be the result of lung cancer that had gone to his brain. We learned that with aggressive treatment, including three to five hospital visits a week for chemotherapy, he would live perhaps four months.

Torch was no doctor, but he knew that he wanted a life of quality, not just quantity. Ultimately, he decided against any treatment and simply took pills for brain swelling. He moved in with me.

We spent the next eight months having fun together like we hadn't had in decades. We went to Disneyland, his first time, and we hung out at home. Torch was a sports nut, and he was very happy to watch sports and eat my cooking. He had no serious pain, and he remained high-spirited.

One day, he didn't wake up. He spent the next three days in a coma-like sleep and then died. The cost of his medical care for those eight months, for the one drug he was taking, was about \$20.

As for me, my doctor has my choices on record. They were easy to make, as they are for most physicians. There will be no heroics, and I will go gentle into that good night. Like my mentor Charlie. Like my cousin Torch. Like so many of my fellow doctors.

—Dr. Murray is retired clinical assistant professor of family medicine at the University of Southern California. Adapted from an article originally published on Zocalo Public Square.

STATEMENT OF SENATOR SUSAN M COLLINS
"EMPOWERING PATIENTS AND HONORING INDIVIDUAL'S CHOICES:
LESSONS IN IMPROVING CARE FOR INDIVIDUALS WITH ADVANCED
ILLNESS"
SENATE SPECIAL COMMITTEE ON AGING
JUNE 13, 2012

MR. CHAIRMAN, thank you for calling this hearing to look at "best practice" models of hospice and palliative care for patients with advanced, serious illness and complex care needs.

Advancements in medicine, public health and technology have enabled more and more of us to live longer and healthier lives. When medical treatment can no longer promise a continuation of life, however, 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 and needs. Clearly there is more that we can do in this country to relieve suffering, respect personal choice and dignity, and provide opportunities for people to find meaning and comfort at life's conclusion.

Fortunately, there are some wonderful models of coordinated, patient-centered care for individuals with advanced illness in our country. In his cover story in this week's Time magazine, Joe Klein writes about his experience during his parents' final days. His mother and father were patients in the Fairways, a Pennsylvania nursing facility in the Geisinger health care system.

Both parents had multiple and complex health conditions including dementia. Prior to their admission to the Fairways, Mr. Klein said that there was no coordination among the "flotilla" of physicians involved in their care. All of this changed at the Fairways.

He was consulted about every development or adjustment of medication. While he still characterized his parent's decline as "horrific," he wrote that he no longer felt so guilty and frustrated. He was part of a team that made their passage as comfortable as possible.

MR. CHAIRMAN, I ask unanimous consent to include Mr. Klein's article in the hearing record.

On a more personal level, one of my dear friends was recently a patient at the Hospice of Southern Maine's Gosnell Memorial Hospice House. I had the opportunity to see first hand what compassionate, high-quality, and seamlessly coordinated care can mean for patients with advanced illness and their families.

In most cases, hospice care enables dying patients to remain in the comfort of their homes, free from unnecessary pain and surrounded by friends and families. The Gosnell Memorial Hospice House in Scarborough, Maine, provides an alternative for those individuals for whom care in the home is not possible or is no longer sufficient. It provides a comfortable and attractive home-like setting for hospice patients and their families where they can receive advanced, patient-centered care in their final days.

From pain and symptom management, to psychological and spiritual support, to delivering longed-for scones to accompany a patient's tea, the care at the Gosnell Memorial Hospice House is first rate. It is making a tremendous difference for patients and their families and should serve as a model for the rest of the nation.

Again, Mr. Chairman, thank you for calling this hearing. I know that this issue is a personal passion for my colleague from Rhode Island, and I look forward to learning more about ways to improve the quality of care for people with advanced illness who are approaching the end of their lives.

Senate Special Committee on Aging

Senator Herb Kohl (D-WI), Chairman

Hearing Title: "Empowering Patients and Honoring Individual's Choices: Lessons in Improving Care for Individuals with Advanced Illness"

Hearing Date and Time: June 13, 2012, 2:00 PM EDT

Name and Address of Submitting Organization:

ADVault, Inc. (www.MyDirectives.com)
Scott Brown, President
Jeff Zucker, CEO
17304 Preston Road, Suite 800
Dallas, Texas 75252
Tel: (972) 733-6814

Chairman Kohl and distinguished Committee Members,

We applaud you for holding a hearing to engage thought leaders on this important topic and are pleased to have the opportunity to submit this statement for inclusion in the record of the hearing on “Empowering Patients and Honoring Individual’s Choices: Lessons in Improving Care for Individuals with Advanced Illness.”

We had the benefit of listening to your comments and the testimony of your excellent panelists last week. Senator Kohl was right to open with a reference to Dr. Murray’s article “Why Doctors Die Differently” and fret that paper-based living wills are often too vague to be truly meaningful. When Senator Collins referenced the timely Joe Klein *Time* Magazine cover story, and when Senator Whitehouse accurately stated the facts about Medicare beneficiary end-of-life bedstays in hospitals and ICUs, we were relieved to hear your concern that patients need to have a voice, even when they can’t speak for themselves, in order to improve our end-of-life healthcare. We agree that “patient-centered healthcare” must not be a buzzword – it must instead be a commitment across the healthcare continuum, especially at the end of life when citizens are the most vulnerable.

The question is how?

Your panelists had some excellent comments and recommendations. As Vince Mor and Albert Gutierrez correctly stated, individuals and their caregivers must have conversations on medical treatment wishes *early and often*. Moreover, as Mr. Gutierrez illustrated so well, documented expressions of patients’ treatment wishes must be able to be located and retrieved when they’re needed most. When Mr. Gutierrez told you how he’d helped his father document his advance directives, but that his sister couldn’t find them as the ambulance rushed to his father’s house, we were reminded of similar stories in our own lives and, unfortunately, in the stories of too many others across the country.

During the question and answer portion of the hearing, Senator Manchin and Mr. Gutierrez asked each other, “Isn’t there an app for that (meaning, having advance medical directives available 24x7)?” We are proud to say, “There is an app for that!”

The emotional sagas within our own families caused us to search for a better way to ensure the highest quality care coordination services for patients. For years we researched why people do or do not create directives – how useful are they to the doctors, caregivers, and family members when they can be found? How efficient is the workflow inside today’s hospitals, and what happens when patients don’t have directives?

We analyzed the research and interviewed global thought leaders on the topic. We studied the wonderful 2009 Report to Congress authored by Judy Peres for HHS.¹ We tested solutions in focus groups, with doctors, and inside a major hospital system. Finally, earlier

¹ *Advance Directives and Advance Care Planning: Report to Congress*, prepared under contract #HHS-100-03-0023 between the U.S. Department of Health and the RAND Corporation (August 2008). See http://aspe.hhs.gov/_/office/specific/daltcp.cfm.

this year, we went live with MyDirectives.com – the “app” that Senator Manchin and Mr. Gutierrez thought should exist. Completely free to consumers, MyDirectives helps people create high-quality advance care plans that include advance medical directives. Users can update, store and print their advance care plan at any time. We help users share them with family and friends, and we encourage those conversations that both Committee Members and the distinguished panelists so rightly recommended. We let consumers attach video and audio messages, we ask questions that allow users to express their views – not just a “yes” or “no” answer – and, perhaps most importantly, we’ve created the technical hooks to the major electronic medical records platforms around the world so the advance care plans can be found the instant a patient is being admitted. After all, what good is a directive if it can’t be found? What good is a signature on a legal piece of paper that nobody understands and family members aren’t even aware of? What good is a directive when the doctor doesn’t know the first thing about the patient?

So, you might wonder what can/should Congress do if MyDirectives.com has done it all?

Here are some suggestions:

1. Ask CMS to put its beneficiaries – our grandparents, parents, us! – in charge of their own healthcare by encouraging us to protect our voices by creating our digital advance directives.
2. Ask the DoD and the VA to do the same thing with our active military and veterans. As Americans we find it extremely unfortunate that we send young men and women overseas putting their lives on the line to protect us, and we don’t require them to complete a digital advance medical directive so we can do our best to understand and honor their wishes in the event of catastrophic injuries.
3. Ask CMS to follow the strong recommendation of the HIT Policy Committee, the AMA, the Joint Commission, and the National Quality Forum, and make advance directives a core requirement of Meaningful Use Stage 2, with the requirement being that certified EHRs document in a prominent part of the individual’s current medical record whether the individual has executed an advance directive *and include a link to a copy of the directive when available*. That would result in all healthcare systems receiving federal funds for “meaningful use” of electronic health records ensuring that those EHRs include a link to a digital directive database such as MyDirectives.com so that the directives can be found and incorporated into the doctor’s plan for how best to treat the patient.
4. Finally, let us once and for all, amplify the leadership shown by this Committee to even talk about the issue of advance medical directives. Advance directives and end-of-life planning should no longer be discussed with hushed, morbid tones and a box of tissues. It is not an issue only for the frail and the elderly. As Dr. Mor stated so well, one of the major failings of our society right now is that not enough people have these conversations early and often. It is too late to have the discussion in the hallway outside of the ER. Every adult 18 and over needs a baseline digital advance directive, and that directive should be easy and free to update as his/her life evolves. Some of us might not remember, but there was a time when women died of a “woman’s disease” because society was afraid to say the words “breast” and

“cancer.” We take for granted today that healthy people discuss organ donation as a choice long before a health emergency makes the issue relevant. We have evolved, and it is time we extend that progress to advance medical directives. Having a good-quality advance directive, always available and electronically linked in a secure way to an electronic health record is a responsible action for all adults.

In summary, the Government’s noble, long-stated goal of scalable widespread use of advance directives is possible. Today. Ladies and gentlemen, we can do better. This government can demonstrate bold leadership by ignoring the politics and doing the right thing: empowering citizens to protect their voice.

The United States Constitution gives each American rights that do not end when they cease to be able to communicate.

We applaud this Committee for seeking solutions, and we stand ready to help you see what a difference you can make by ensuring your constituents protect their voice.

Thank you.



One Penn Center West, Suite 229 • Pittsburgh, Pennsylvania 15276-0100

Statement for the Record
by the
Hospice and Palliative Nurses Association
for the Select Committee on Aging
U.S. Senate
Hearing Convened on June 13, 2012

**Hearing Title: "Empowering Patients and Honoring Individuals'
Choices: Lessons in Improving Care for Individuals with
Advanced Illness"**

On behalf of the Hospice and Palliative Nurses Association (HPNA), the nation's only professional nursing organization dedicated to promoting excellence in hospice and palliative nursing care, we commend Senator Sheldon Whitehouse for convening this hearing and very important, yet often ignored, discussion addressing aging, advanced illness and honoring individuals' choices. This issue is at the foundation of much of the work of HPNA and its 11,000 members in all 50 states. We thank you for the opportunity to submit a statement for the record and would like to further offer our expertise to the Senate Select Committee on Aging for any future activity on these critical patient issues.

Summary

The assurance of choice for seriously and progressively ill patients is one of the core missions of HPNA. Informed consent is the gold standard for making choices in health care in the United States. Informed consent directly supports patients and families by presenting all treatment and care options in a balanced manner and supporting the individual and his/her family to make their own choices. Nowhere is this more important than in the care of people with life limiting conditions. Patients have a right to know all of their treatment options at the time of the diagnosis and at each treatment juncture, and to be provided with consultations that help them make informed choices that match their goals.

Palliative care is a philosophy of and system for delivering patient-centered, interdisciplinary care to persons with serious, progressive illness. It includes a focus on quality of life, function, decision making and opportunities for personal growth. Palliative care can be provided concurrently with disease-modifying treatments and provides assistance in identifying health care goals, system navigation, and aggressive pain and symptom management.

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Growing research evidence demonstrates that palliative care supports patient choice and improves quality of life. Patients who understand all of their treatment options may choose to forego medical treatments that are not aligned with their goals for care or that they consider too burdensome. While not its primary aim, palliative care reduces costs of care by supporting patients' treatment choices that match their personal goals and values. All patients with life limiting conditions should be informed about palliative care along with other medical treatment options to support them through one of life's most difficult challenges. **Palliative care is an important and still underutilized treatment option.**

Issues:

- Informed consent must include balanced information about all treatment options.
- Patients who don't receive open, honest communication about severity of illness and medical treatment options often suffer unnecessarily with poorly managed pain and symptoms, anxiety and no support to plan ahead for future care when they are no longer able to voice their wishes.
- Palliative care is underutilized, yet is available broadly across the United States through more than 5,000 hospice programs and 1,500 hospital-based palliative care programs.
- Professional nursing care is critical to achieving the patients', families', and communities' goals of care at the end of life.

Rationale:

- Americans worry that they might not be told about all treatment options during serious illness.
- Americans are not aware of palliative care.
- Palliative care nurses are expert in communicating with and supporting seriously and progressively ill Americans and their families.

Recommendations:

- Include in future legislative and regulatory policies a requirement that advance practice nurses and physicians offer seriously, progressively ill patients information and counseling concerning palliative and end of life options for care and treatment.
- HPNA is the authority of palliative care nursing and as such, stands ready to participate in initiatives to enhance patient choice and access to quality palliative care.

Written Statement of
Allison Herwitt
Legislative Director
Human Rights Campaign

To the

Special Committee on Aging
United States Senate
Hearing to Examine Empowering Patients and Honoring Individual's Choices
June 13, 2012

Mr. Chairman and Members of the Committee:

My name is Allison Herwitt, and I am the Legislative Director for the Human Rights Campaign, America's largest civil rights organization working to achieve lesbian, gay, bisexual and transgender (LGBT) equality. By inspiring and engaging all Americans, HRC strives to end discrimination against LGBT citizens and realize a nation that achieves fundamental fairness and equality for all. On behalf of our over one million members and supporters nationwide, I am honored to submit this statement into the record for this important hearing on empowering patients and honoring individual's choices focusing on lessons in improving care for individuals with advanced illness.

Forty years ago, this Special Committee held the first national hearings on "Death with Dignity." Since that time, our nation has made strides in empowering patients and respecting patient autonomy— especially in the area of end of life decision making. These measures include the regulation of long-term care facilities, the acceptance of advanced health care directives, caregiver support programs, and increased access to hospice care. In each of these areas, LGBT seniors face real and significant barriers to equal access on account of their sexual orientation and gender identity.

There are an estimated 1.5 million LGBT seniors in America today. By 2030, this number is expected to double.¹ LGBT seniors are an extremely vulnerable population, many of whom will have to face the challenges of advanced or terminal illness without the traditional support systems and legal protections that other seniors can take for granted. As LGBT adults enter their later years, they are forced to navigate a series of unique and complex barriers. Discrimination in housing, employment, and healthcare has made many LGBT older adults subject to an increased risk for social isolation and higher poverty rates. The lack of relationship recognition, continued harassment by peers and healthcare providers, and the impact of lifelong discrimination silences many LGBT older adults and their families.

The Nursing Home Reform Act of 1987 guaranteed the "dignity," "respect" and "self-determination" of each resident. In spite of these broad protections, LGBT residents continue to

¹ *Improving the Lives of LGBT Older Adults*, 2010. Services and Advocacy for Gay, Lesbian, Bisexual and Transgender Elders (SAGE) and the Movement Advancement Project. Available at: <http://www.sageusa.org/specialevents/home.cfm?ID=71>.

experience high rates of discrimination by caregivers, nurses, and other residents. This discrimination can take many forms including bullying and harassment, as well as failure to provide necessary daily care like bathing. Some long-term care facilities refuse to recognize transgender residents' gender identity, often insisting on using the incorrect name and making the resident dress in gender inappropriate clothing or room with a member of the opposite sex. This wide spread harassment and discrimination too often leads to depression, failure to thrive, and suicide.

Fear of discrimination also deters many LGBT seniors from seeking the help they might desperately need. Thirty percent of LGBT seniors in a recent survey reported that they believed discrimination in a long-term care facility was inevitable.² This well-founded fear makes many LGBT seniors go to great lengths to avoid being admitted to a long-term care facility. Fearing harassment and discrimination at the hands of home health aides, LGBT seniors are also less likely to use supportive services. This fear extends to palliative hospice care that is designed to affirm the value of each life and maximize the quality time an individual gets to spend with loved ones. The hospice promise of peace, comfort, and dignity should apply equally to all Americans, but the fear of mistreatment deters LGBT seniors from seeking this care. Without these services, LGBT seniors are at an even higher risk of social isolation.

Managing end of life care for a loved one can be a stressful and exhausting experience. For LGBT older adults, however, the accompanying heartbreak is too often compounded by discrimination and non-recognition. Caregiver support programs acknowledge the unavoidable pain of bereavement, as well as the heavy toll that caregiving can exact in terms of the caregiver's emotional, physical and financial wellbeing. These programs rarely recognize same-sex partners.

When LGBT seniors plan for end of life care and treatment, many rely on close friends or their spouse or partner. Every state has legislation recognizing advanced health care directives designed to insure that the wishes of the patient remain paramount. Designating a spouse or partner as a health care power of attorney is the clear choice for most adults facing an advanced illness. Having shared decades together, a spouse is uniquely positioned to make the hard decisions that are in the best interest of the patient and their family. More importantly, they are also the most likely to be aware of their partner's wishes, if he or she can no longer communicate. While virtually all states recognize a spouse as the first in line to make these intimate decisions, same-sex spouses are denied this recognition. Instead they must rely on prepared legal documents to ensure that their relationships and wishes are respected at this critical time.

Health care powers of attorney and advanced directives can provide LGBT seniors with some peace of mind as they struggle with an advanced illness. However, access to these legal documents is not universal, nor is it fool proof. In order to be effective, these documents and decisions must be respected by nurses and facility staff. Respect for legal documents designating a same-sex partner or spouse varies from state to state, facility to facility, and caregiver to caregiver. The failure to follow the clear direction of a legal document allows bare prejudice to trump patient self-determination.

² *Metlife, Out and Aging: The Metlife Study of Lesbian and Gay Baby Boomers* (2006). Available at <http://www.metlife.com/FileAssets/MMI/MMIStudiesOutandAging.pdf>.

The Centers for Medicare and Medicaid Services (CMS) recently revised its standards prohibiting discrimination against LGBT people in visitation for hospitals receiving reimbursements under its federal programs. The agency also requires hospitals to respect an advanced directive or health care power of attorney designating a same-sex partner or spouse as a decision maker. However, as we have seen throughout the country since the implementation of this new policy, education of staff will be key in guaranteeing an end to this discrimination. This policy also does not protect same-sex partners if the patient fails to formally designate the partner as a health care power of attorney.

Unfortunately, the CMS protections for hospitals noted previously do not extend to LGBT older adults in nursing homes and long-term care facilities. Without uniform protections in place, LGBT seniors in these facilities remain vulnerable to harassment and discrimination. Clear non-discrimination guidelines from CMS and uniform adoption of cultural competence standards would help alleviate LGBT older adults' fears and empower patients to be more active in their own care. Long-term care facilities, caregivers, and hospital staff must receive effective cultural competence training, and they must be held accountable for actions that infringe on the dignity and self-determination of LGBT seniors.

Across America, frail LGBT seniors living in long-term care facilities wake up each morning worried about what new indignities they will face at the hands of the other residents or staff who harass and bully them on account of their sexual orientation or gender identity. Other LGBT residents, who have decided to be closeted, face yet another day when they will not be able to share any of their memories of a life well lived. Still other LGBT seniors wake up in their apartments and homes too afraid to seek any assistance, preferring to die alone rather than risk encountering bias and discrimination.

The Human Rights Campaign urges Congress to address these issues and this growing need. Congress and the President have recognized the importance of regulating long-term care facilities, respecting advance directives, supporting caregivers, and increasing access to hospice care and have taken steps over the past forty years to improve the quality of life for millions of Americans and their families and provided much needed solace. Congress must now act to ensure that these measures apply equally to all seniors regardless of sexual orientation or gender identity, and that LGBT seniors are afforded the same level of dignity, respect, and self-determination.



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June 13, 2012

Mr. Chairman and Members of the Committee:

Thank you for hosting this important hearing, entitled “Empowering Patients and Honoring Individual’s Choices: Lessons in Improving Care for Individuals with Advanced Illness.” We appreciate the opportunity to submit this statement into the record on the relationship between this issue and the unique challenges faced by lesbian, gay, bisexual, and transgender (LGBT) older adults. Services & Advocacy for GLBT Elders (SAGE) is the country’s largest and oldest organization dedicated to improving the lives of LGBT older adults. For more than 30 years, SAGE has pioneered programs and services for the aging LGBT community, provided technical assistance and training to expand opportunities for LGBT older people across the country, and provided a national voice on LGBT aging issues. In partnership with constituents and allies, SAGE works to achieve a high quality of life for LGBT older adults, supports and advocates for their rights, fosters a greater understanding of aging in all communities, and promotes positive images of LGBT life in later years.

As the number of Americans age 65 and older surges over the next few decades, the number of LGBT older adults is estimated to double to 3 million by 2030. As with other marginalized communities, LGBT older adults face significant barriers and profound disparities that place them in great social need. The available research shows that: LGBT elders have fewer sources of support as compared to their heterosexual peers; face higher poverty rates; and experience poor health and health access. In addition, many enter the aging system with the harmful physical and emotional health effects of having lived through a lifetime of discrimination. Because of these profound challenges, LGBT older adults require unique services and supports that are scarce and severely underfunded in every part of the country. Many live in areas that lack vital, LGBT-affirming services that can improve their economic security, social support, and overall health and well-being. Further, while many Area Agencies on Aging (AAAs) are willing to offer LGBT cultural competence training to their staff, very few offer LGBT-specific programs or outreach. Overall, there is insufficient research on the needs of LGBT older people, the programs that could reduce these disparities, and whether aging providers are effectively serving them.

As LGBT older adults face advanced illness, many face challenges not faced by their heterosexual counterparts. Some of the most unconscionable are laws that stand in the way of LGBT people taking care of those they love, in life and in death. Under federal law and most state laws, LGBT people are not granted family or medical leave to take care of a sick or terminally ill partner. Furthermore, LGBT people could be excluded from medical decision-making for a partner. Finally, upon the death of a partner, LGBT people are often denied making end-of-life decisions about last rites, funerals, and disposition of remains.

Government programs and laws supporting the care of loved ones at home generally presume that care is provided by a spouse or biological kin. Because LGBT older adults are generally excluded from marriage, and are often single, their caregivers are often “families of choice,” such as partners and friends. As a result, LGBT elders might be denied leave to take care of a sick partner or friend. The federal Family Medical Leave Act (FMLA) requires public and large private employers to grant up to 12 work weeks of unpaid annual leave to care for a spouse, child or parent with a serious health condition. The FMLA provides these caregivers flexibility, leave, and a job guarantee. LGBT people, however, who are caring for their partner or other loved ones risk losing their jobs because families of choice are not recognized by the FMLA. This exclusion can also prevent an LGBT elder from receiving needed care from a partner or loved one. To make matters worse, most state medical leave laws also exclude family-of-choice caregivers.

Many LGBT older adults also face barriers to visitation and medical decision-making, which becomes all the more crucial as individuals face advanced illness. Many heterosexual spouses take for granted that they will have access to each other’s hospital rooms and be in charge of each other’s medical decisions, should one spouse be incapacitated. Same-sex couples have no such assurance. Unless an LGBT elder has specific (and often expensive) legal arrangements in place, most states give priority to opposite-sex spouses and biological kin for medical and long-term care decision-making and visitation, rather than life partners or families of choice. President Obama of course mandated that all hospitals receiving Medicare and Medicaid payments grant their patients the right to designate visitors and medical decision makers. This mandate, however, does not apply to nursing homes and assisted living facilities—and anecdotal data shows that LGBT older adults still face extra hurdles in acting as a default medical decision maker for their partner. While a heterosexual couple is rarely challenged to produce a marriage license, same-sex couples must often produce paperwork proving their relationship or medical decision-making authority, which they might not have on hand in a medical emergency. For example, if an individual is rushed to the hospital and is not carrying these relevant documents, a loved one could legally be denied access. Worse, even when a couple has the appropriate documentation, there have been numerous incidents of hospitals disregarding legally valid medical powers of attorney or advance healthcare directives, or prohibiting same-sex partners from visiting with one another, even in cases involving critical injuries and illnesses. While these types of practices are illegal, many LGBT people do not have the resources to challenge these actions, nor can these actions usually be resolved in the rushed timeframe of a medical emergency.

Lastly, many partners of LGBT individuals with advanced illnesses are excluded from end-of-life decision-making, including funeral decisions and disposition of remains, with states prioritizing biological kin for these tasks unless an LGBT elder has the appropriate legal documentation in place. Again, practices vary from state to state. Some states offer a separate document or form that confers end-of-life decision-making authority. Other states allow an individual to confer this authority within another document such as the health care power of attorney or a will. And other states have weak protections for the deceased’s preferences and only respect their wishes if they have a prepaid funeral (e.g., West Virginia). In the worst of examples, some states may allow next of kin to challenge and override any decisions made by the deceased individual (e.g., Michigan).

Despite advances in LGBT civil rights, the tendency for LGBT older adults to go "back in the closet" is particularly pronounced in situations where they are most vulnerable - such as when accessing home health care or residing in assisted living or residential care facilities. Many older adult care providers never stop to consider that their older clients may be LGBT and the resulting unique barriers they face. These providers often cannot and will not address these challenges alone. Both federal law and aging policy must be modernized to address the unique needs of this growing population. SAGE asks this committee to address the critical issues facing LGBT older adults and we look forward to working with the committee to address the needs of this most vulnerable population.

Sincerely,

Aaron Tax
Director of Federal Government Relations